

# **Taking Control of Your Financial Health During and After a Health Crisis**

**Roundtable Discussion Transcript**

**Wednesday, November 7, 2012**

**Presented By**



**SHARSHERET**

**Sharsheret – Your Jewish Community Facing Breast Cancer**

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The Jewish Women's Foundation of New York**

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**I. Introduction**  
**Shera Dubitsky, MEd, MA, Clinical Supervisor, Sharsheret**

Shera Dubitsky: Thank all of you for joining us this evening for Sharsheret's National Teleconference on New Advances in Gynecological Health Before and After Cancer.

Good evening again to everybody. I want to thank you all for coming to the taping of Sharsheret's roundtable discussion. My name is Shera Dubitsky and I'm the clinical supervisor at Sharsheret. We appreciate all of you again who have weathered the storm to join us in person and again, we want to welcome those of you who are listening from all across the country who are comfortably sitting in your home, perhaps enjoying a meal as we are here as well.

I would like to begin by thanking the Jewish Women's Foundation of New York for their generous grant and for their recognition that while advances in medical technology mean that Jewish women may have a better chance of physically surviving serious illness, the overwhelming financial issues associated with treatment and recovery could be devastating to their financial health, particularly during these challenging times.

For those of you who are not familiar with Sharsheret, Sharsheret is the Hebrew name for chain and we are a national, not-for-profit organization supporting young women and their families of all Jewish backgrounds who are facing breast cancer. We are supporting women who are at high risk of developing breast cancer and for all those who are already diagnosed. We are connecting women to a community in a way that feels most comfortable while taking into consideration the stage of diagnosis, whether or not you are undergoing treatment, and also for those women who are concerned about their connections to Judaism. We are providing educational resources and we are connecting people with peer supporters and with medical experts and we also have a program for those who are facing ovarian cancer. As women are coping with illness, they are increasingly concerned about insurance coverage, financial planning, estate planning and general issues of financial and legal wellness. As with all of Sharsheret's programs, we begin with our callers. Every day, we're hearing about your financial concerns and we are determined to respond to your needs. We hosted a focus group, I was trying to remember how long ago, probably about six months ago, to explore specific areas that are triggering the highest anxieties and really, across the board, the loudest message from the focus groups and also from the calls that we get every day, is that managing the financial aspect of illness feels like a full time job and that it begins at the time of diagnosis and it's one of those issues that continue to linger far beyond treatment.

Our panel tonight will discuss how to navigate your insurance company, how you can better understand your disability rights, to offer guidance on financial planning and how. We will also hear a personal story from a woman who was pro-active in seeking financial assistance. After the presentations, we will have an interactive discussion with the panelists. Our goal this evening is to establish an informative and intimate dialogue between our experts and those of you who are seeking financial help. The goal for tonight is empowerment.

Tonight's conversation will be taped, transcribed, and live streamed through our website at [www.sharsheret.org](http://www.sharsheret.org). We are taping on the East coast and I'm sure that many of you are aware that we are post-storm with Sandy and we are now, if you will look out the windows, there's a nor'easter. So, two of our speakers were unable to

join us in person but we are very grateful that they have agreed to join us over the telephone because they also recognize the importance of this topic. So with that, I would actually like to introduce Joanna Morales who is joining us via telephone. She is a cancer rights attorney, author, speaker and chief executive officer of Navigating Cancer Survivorship, a national not-for-profit organization connecting people to cancer survivorship resources. She also serves as the principal of North Star Alliances, a business and non-for-profit consulting and service firm. Ms. Morales has spent many years working on behalf of individuals with cancer. She has presented hundreds of educational seminars throughout the country for patients, survivors, caregivers, healthcare professionals, advocates, lawyers, employers and the general public. In addition, Ms. Morales serves on numerous cancer community committees and boards. She has published in a variety of publications and contributed to a book. Ms. Morales has received numerous awards and recognition for her service to the cancer community and her work in the area of legislative advocacy. We are privileged to have her here with us this evening.

So, Ms. Morales, I will go ahead and work the slides for you, if you just tell me when to move on to the next slide. So, Ms. Morales, the floor is yours.

## **II. Accessing Insurance Joanna Morales, Esq, Navigating Cancer Survivorship**

Thank you so much. I am again sorry that I am not able to be there in person tonight but my purpose tonight is to talk to you a little bit about health insurance. Health prices typically bring with it a need for healthcare and having health insurance is an important way to protect your financial self while accessing healthcare. But if you have a pre-existing medical condition like cancer, knowing what your options are to keep, or to get health insurance coverage.

So I'm going to provide you with an overview of some of the ways to find insurance, how to keep it and how to get insurance if you're uninsured. And I want to start with COBRA. And COBRA is a federal law that allows you to keep employer's sponsored health insurance coverage if you leave your job, if you reduce your hours or if you age out of your current health insurance plan. Now this is a great way for you to keep your health insurance coverage that you're getting through an employer but the downside is that you're responsible for paying the whole premium of what your employer was paying for your health insurance coverage. And I always say that we don't appreciate what our employers pay for our health insurance coverage until we have to write that check ourselves. So there are some programs out there to help pay for COBRA premiums or health insurance premiums or co-pay assistance. So there are some ways to kind of alleviate the expense of COBRA. It is a good way to keep your coverage especially if you are in the middle of treatment because then you don't want to have to worry about changing providers and if any of your providers don't take a different kind of health insurance coverage, then you're kind of stuck. Now, COBRA only applies to employers of twenty or more employees so there may be a version of COBRA for smaller employers in your state. Now, COBRA only lasts between eighteen and thirty six months, depending on you qualifying for that. So, for example, if you lose your job and you're eligible for COBRA, you can seek COBRA coverage for up to eighteen months but then the question becomes well, what do you do if you have pre-existing condition like cancer after your COBRA coverage ends? And that's where HIPAA comes in.

HIPAA is the Health Insurance Portability and Accountability Act and most people are familiar with HIPAA because of the privacy protection. But HIPAA was a federal way

which was also meant to protect people with pre-existing conditions from discrimination in the health insurance market but only in certain circumstances. So it's only providing these protections moving between two group plans, like when you're moving between employers or when you're moving from a COBRA plan to a HIPAA plan. I'll explain that a little bit more in a second. But the most important thing to remember about HIPAA is sixty three days. You cannot have a gap in your health insurance coverage longer than sixty three days or you'll lose some of the protections that HIPAA offers. So if your COBRA is about to end and you're looking at your HIPAA plan options, or if you're going to a new employer, you never want to have a gap between any of your insurance coverage that lasts longer than sixty three days. Now when COBRA ends, you may be eligible for what is called a HIPAA Guaranteed Issue Plan and they call it that because they are guaranteed to have it issued to you. But in order to get a HIPAA plan, you actually have to exhaust your COBRA coverage or if you are eligible for COBRA state insurance coverage and you can't be eligible for any other group plans or Medicare or Medicaid and, again, you can't have that gap last longer than sixty three days. And there's three options for HIPAA plans depending on the state that you live in. So for both New York and New Jersey even, so every insurance company that writes policies in the individual market in New York and New Jersey also have to offer a HIPAA plan so you can't be denied. However, you also are not protected in terms of price so HIPAA plans are allowed to charge you what they decide they want to charge you. So HIPAA plans can also be expensive. And, again, I would point people towards the financial assistance resources to pay for health insurance premiums.

Now HIPAA also provides some protection for when you are moving between plans. So if you are moving between two jobs and you're worried because you have a distinct condition about what's going to happen at that new employer, HIPAA provides some protection. And the way that it does that is through limiting a pre-existing condition inclusion period. And what that is, is a period of time that a new insurer can say to you, "we're going to give you health insurance coverage but we're not going to cover anything related to pre-existing conditions". So if your pre-existing condition is cancer and you break your arm and have to go to the emergency room because you are in a car accident, they are going to cover that but they're not going to cover anything related to cancer treatment and that's obviously a problem. So, HIPAA limited those pre-existing conditions inclusion period to twelve months. But then it also gave you a way to eliminate it further or reduce it or get rid of it entirely and it did that through something called Creditable Coverage. And Creditable Coverage is credit that you get for time that you had health insurance coverage in the past. So if you worked at a previous job and had six months of credible health insurance coverage, you can use that six months, subtract it from that twelve month inclusion period that your new insurance plan is imposing and you'll only face a six month inclusion period. So it requires you to do a little bit of math but you can actually get rid of any exclusion period entirely. But the key to all of this is that you can't have a gap between your insurance coverage that lasts longer than sixty three days. So I know that was kind of fast and I'm going to keep moving through and obviously, give questions we can come back to at the end of the program.

So in terms of ways to get insurance coverage, if you have a pre-existing condition, that can be really difficult because if you try to go and buy an individual health insurance plan with a pre-existing condition like cancer, it's pretty impossible and if you, even if you are offered an insurance plan and chances are it's going to be so expensive that you can't afford it anyway. So there are a few options out there for individuals with pre-existing conditions and the first one that I want to talk about is the Pre-Existing Condition Insurance Plan or PCIP. And PCIP was actually created by

the Affordable Care Act or what most people refer to as health care reform in 2010. And PCIP is for individuals who are U.S. citizens or lawful residents who have a pre-existing condition and have been uninsured for the previous six months. So this isn't necessarily a way to keep your health coverage if your COBRA is ending or if you are on a HIPAA plan and are looking for the next option, this is really for individuals who have been uninsured for a period of time and are trying to get access to health insurance coverage. So for more information about PCIP which is available in every state, you can go to [PCIP.gov](http://PCIP.gov) and you can find very clear information about the PCIP plan in your state, what the prices would be, the coverage, all of that detailed information in a very usable format.

So there are also state level high risk insurance pools or major risk insurance and they aren't available in every state. So there's only about thirty five states that have them and I mention them because I'm going to assume that not necessarily everyone watching is from New York or New Jersey. Those who do not have major risk or high risk insurance pools but if you wanted to find out if your state had a PCIP plan, you can actually go to [Healthcare.gov](http://Healthcare.gov). [Healthcare.gov](http://Healthcare.gov) is a website that is run by the U.S. Department of Health and Human Services that has information about what your health insurance options are. So you can go to that website and on the bottom left hand corner, it asks you what state you live in and then they ask about four more questions, about who you are and the type of health insurance coverage that you're looking for and your medical conditions, if you have any. And it will tell you what your insurance options are specific to you in your state. So there are really excellent pools to find out what your options are. So maybe, even if you have health insurance coverage and you're kind of looking to see what your other options are, that's the place where you can go. So to find out information about the high risk insurance pools in your state or any other kind of health insurance coverage, you can go to [Healthcare.gov](http://Healthcare.gov).

And then the two federal health insurance programs, Medicare and Medicaid are also options for individuals with pre-existing conditions. Medicare is the federal program for individuals who are sixty five or older or have a disability under Social Security standards and Medicaid is for individuals with a low income and some other type of eligibility requirement which could be that you are a pregnant woman or most likely when we're talking about the cancer community, you're qualifying through something called the Aid Find and Disabled Program. So you're accessing Medicaid because you have a low income and you have a disability and it's cancer.

So those are some of, just a brief overview of some of the options. So on the next slide, I want to talk about some of the things that healthcare reform has brought us that has been particular useful to individuals with pre-existing conditions such as cancer. So if you could actually go to the next slide. Okay, thank you. Thanks. And the first thing that I want to mention is that there are two ways where the Affordable Healthcare Act specifically helps children and adolescents and young adults. And the first is that children under the age of nineteen can't be denied health insurance coverage anymore, regardless of the fact that they have a pre-existing condition. And that's actually pretty significant. I've been doing this for about eighteen years and I never thought that I would see the day. So children under nineteen can't be denied health insurance coverage and they can't be charged more because they have a pre-existing condition.

The second thing that it did was that adolescents and young adults can stay on their parents' health insurance plan until the age of twenty six. And this has been pretty significant. We've seen in the last year about three million young adults get access to

health insurance coverage, specifically because of this provision. And then the Affordable Care Act also eliminated lifetime caps and will eventually eliminate entirely annual caps and what those are, are on your insurance policy. An insurance company can previously say, once you hit a million dollars in healthcare, we're not going to cover anything else and that's it. And we know with the cost of chronic medical conditions such as cancer, can be extremely expensive and so that was a significant benefit for the cancer community to eliminate those lifetime caps. And the same thing with annual caps as well. We were seeing annual caps that were maybe only \$75,000 a year or \$25,000 a year and that was really a huge financial burden on individuals with those policies because then they would have to pay for all the rest of their healthcare out-of-pocket. And then the Affordable Care Act also eliminated mercision and mercisions are what insurance companies would do once you tried to file a claim on your health insurance policy. So if you filed a claim and said that you needed cancer care, they would go back to your original application and try to find a reason to cancel your policy. Maybe you left off something, you got a state wrong on previous healthcare that you've had and then they would cancel your policy. And this was happening all the time and most often in the cancer community.

And then healthcare reform did tons of other things but the ones that I want to highlight are because they really speak to the financial impact. And there's three preventive care, so there's a list of the six preventative services that you can find on Healthcare.gov and those things include the RCA counseling, mammography for women forty and older on an annual basis. And then obviously if you are high risk, looking, talking with your doctor about doing that more often if necessary, specific preventative solutions that are now free to you if you have health insurance coverage, not paying, so that you're not paying co-pays and co-insurance and it's not being applied to the deductible. So that free preventative care is entirely free to encourage people to actually get preventative care. And then medical loss is a technical term that means that when you, when insurance companies collect your premium. It's what you pay on a monthly basis. They have to pay now, they have to use that money for your care and they have to use eighty to eighty five percent of your premiums on your care. So their administrative costs, their marketing or the other things they do on an administrative level, can't be more than fifteen to twenty percent of the premium that you're paying. And the reason this is significant is not only does it require insurance companies to keep administrative costs down and to give you quality care, they don't, they actually have to give you a rebate and we've seen significant rebates across the country, that 2011 was the first year that this went into effect, I'm sorry, 2012, and we were seeing millions and millions of dollars in each state going back to consumers. So this was actually something that significantly affected people's pocketbooks.

And then there are a number of changes that are coming in 2014 and there are lots of new health insurance options, changes to our system. Some states will actually expand Medicaid to all low income adults and then you don't need to meet a secondary eligibility requirement. So the most significant one that I want to mention is an adult will no longer have to worry about being discriminated against because of their pre-existing condition. So I mentioned that this applies to children already but for adults, we have to wait until 2014 for that to go into affect. So you can no longer be denied coverage because of a pre-existing condition and you can't be charged more. And in addition to not being able to charge you more for having a pre-existing condition, they're also doing away with what's called gender rating where women are actually charged more for their health insurance coverage. This is the way it is now.

So that's a very quick overview of some ways that health insurance have an impact on your financial health because of a health crisis and I'm happy to take questions later.

Shera Dubitsky:

Thank you Ms. Morales. That was a wonderful crash course in accessing insurance. The way that you put it so easily, it really clarifies for us that the health care reform that is hundreds and hundreds of pages. So that was actually very helpful to get an overview. So thank you for that and we will certainly have questions for you after everyone has presented.

Our next speaker is Gabe Hermann. He is a lawyer who practices in New York and New Jersey. He specializes in disability law and has lectured to both legal groups and disability related organizations. Mr. Hermann has appeared on CNNFM, addressing issues about disability claims and we are very grateful to have him share his expertise with us this evening. So, Mr. Hermann, the floor is yours.

### **III. Understanding Disability Rights Gabe Hermann, Esq, Insler & Hermann, LLP**

Good evening everyone. The Social Security Disability program is designed to provide financial assistance to those who are eligible for benefits. There are two types of benefits available, Supplemental Security Income program and the Social Security Disability program. Supplemental Security Income, commonly called SSI, is a program that generally runs parallel with state welfare programs. Typically an SSI beneficiary must have less than \$2,000 in savings or resources, plus an additional \$1,500 can be put aside in an account earmarked for burial funds. The household income limits for an SSI program is based on something called the Federal Benefit Rate, the FBR. This FBR represents both the SSI income limit and the maximum federal monthly SSI payments. In 2012, the FBR was \$698 per month for an individual and \$1048 per month for couples. For Social Security Disability, household income and assets are not considered. The test is whether a claimant is insured. That is, whether he or she has earned enough in each of the five preceding ten years to be eligible for four quarters of coverage.

As of 2013, a quarter coverage is earnings of \$1,160 per quarter so you have four. It's actually, it's funny, years ago you had to earn that quarter of coverage in the quarter of time so January to March, April to June, July to September, and October to December. And if you earned all of it the first month of the year, you were out of luck for the rest of the year. Now five, six years, now, fifteen, sixteen years ago they changed that to quarters of coverage. You can earn all of your earnings in the first month of the year and you're deemed having earned the money until the full, until the end of the year, although they won't credit it to you for purposes of eligibility for disability if applicable until you've satisfied the second quarter, third quarter, fourth quarter, so the end of every month of that quarter. But a safe rule of thumb for earnings is that if you've earned \$1,160 which is the 2013 number, or if you've earned at least \$5,000 in every, in at least five out of the previous ten years, then you're probably eligible for social security benefits. Unfortunately, there is commentary to almost anything that I say. I'm trying to be as general as I can and obviously I'm available to answer questions at the end.

The biggest shortcoming of the Social Security programs is that a non-working spouse who becomes disabled but did not have the opportunity to accrue sufficient quarters of coverage is usually not going to qualify for Social Security Disability benefits. That is, if, for example, a wife doesn't work, her husband supports the

household, hasn't worked in five of the previous ten years, probably won't be eligible for Social Security Disability benefits and that same spouse who is earning over the federal benefit amount, there's no SSI eligibility either. This is unfortunate. The Social Security never really contemplated benefits for non-working spouses under the Social Security Disability program. They focused more on retirement, widows, retirees, people over age fifty or sixty. Unfortunately, once one files a claim, things rarely move quickly through the agency's bureaucracy. The time frames noted on the chart listed here are typical numbers which is initial application until initial decision is usually six months. If you're in New York, then the next step is a hearing request so that's typically twelve to eighteen months before you can get to a hearing. New Jersey, Connecticut, and many of the other states, I'm sorry, since I work primarily in the tri-state area, I don't really focus on the other states, but most states do have this reconsideration step which means, after your initial application and if there's an initial denial, the next step is reconsideration which is three to six months. Usually the decision makers rubber stamp the initial decision. If they don't, and when they rubber stamp, the next step is a request for hearing which is twelve to eighteen months. Fortunately, as noted, New York has eliminated that step one of the process but even so, the waiting times for a typical disability claim are lengthy. Having said that, there are exceptions and here is some good news for the way, unfortunately, not for the people that are suffering the conditions. The primary exception is something called a Compassionate Allowance. These cases are flagged as critical cases by the Social Security Administration and they are absolutely expedited. I've had clients that I file, cancer clients actually, several different types of cancer that I file and I'm not joking when I say within two weeks my clients are contacting me or the agency is contacting me to tell me that the claim was approved.

There are 165 listed disorders and conditions which qualify for this extremely expedited program. One example is item number 19, breast cancer with distant metastasis or where it is inoperable or unresectable. Besides the Compassionate Allowances, Social Security also has a list of disorders and conditions which if properly established, increase the likelihood of a faster resolution. While it won't be a matter of weeks or even days, as it is with the Compassionate Allowance, a properly developed medical file which shows conditions which satisfy the listings, has in my experience resulted in a relatively rapid favorable determination. For specific information on the various cancer related listings, you can Google [ssa listing 13.00](#) if you want to just want to look at the different kinds of medical conditions that fall under these qualifications. SSA listings, Google, trust me, just doing that and you're going to find yourself at Social Security's guidelines and the site.

Medical Benefits. While ideally a person who has an approved disability would immediately be eligible for medical coverage, that is only the case for successful SSI claims, the Social Security Income claims. In those cases, a successful claimant will immediately be eligible for Medicaid which Ms. Morales spoke about briefly. The good news is that the Medicaid program to which the claimant would be eligible is one that's a federal administered program. State programs have their requirements, pregnancy or the age, the disability, the need. You can get qualified for state Medicaid as a "disabled person" by with your doctor's assistance. The thing that needs to be clear is that the insurance company, not the insurance company, the state and the Medicaid program is going to be constantly reviewing and constantly reevaluating you and frankly they don't give you peace at a time when you most need it, which is during the time that you are battling a condition. So the good news with the federal program is if you qualify for SSI, then as long as you're eligible for SSI, you are also eligible for the Medicaid program. Again, it is only for the SSI claimants. This is Medicaid. In virtually all cases, Social Security Disability beneficiaries must

wait twenty four months after the date of eligibility to be eligible for benefits from Medicare. The date of eligibility is actually very different from the date of disability. It's six months later, technically five full months later or twelve months prior to the date and the application is filed, whichever is the more recent date.

A common misperception is that Medicare starts two years after a disability win. That's incorrect. The count begins from the date of eligibility and so in some cases where a claim takes over eighteen months, which as you saw earlier, unfortunately it does happen, eighteen months from the application date, a claimant might be eligible for retroactive Medicare. I rarely recommend that my clients that win in that circumstance pay in the additional prior premium for the Medicare, primarily because you pay in the Medicare, so you pay out your \$100, \$200, \$500, \$1,000, \$2,000 in retroactive premiums and yes, the insurance, the Medicare will pay for the treatment and in theory may reimburse claimant for out-of-pocket medical expenses. The problem is doctors have a different rate for Medicare patients versus regular patients. So trying to get reimbursed the \$10,000, \$20,000 that's Medicare eligible for reimbursement, honestly might be more trouble than it's worth and in truth there are so many of these programs that make out-of-pocket expenses almost, I usually recommend that my clients don't do it but it is an option if somebody is willing or has the means and the records which is the key, the records to do this, it is an option to get reimbursed for retroactive Medicare benefits. Ms. Morales did mention this but I want to mention this, reiterate it as well, that every state does have the Affordable Health Insurance for individuals with pre-existing conditions. I have looked at it, I have made recommendations to my clients. In New York, there are a couple of programs. The range in insurance costs depending on the age of the individual asking for it or seeking it is three to six hundred dollars. Numbers might have changed recently. I haven't looked at it in a while but I have had clients who have been very pleased with it when they have had no other options for health insurance and the, call it the rack rates, the market rates were just so prohibitive or unavailable because of the pre-existing condition.

Continuing Disability and Continuing Disability Review. Ideally, once you've finally been approved for disability benefits, the agency will leave you alone. Unfortunately, the regulations governing Social Security do authorize the administration to review your claim. Typically when that happens, it's between three and five years after an initial award, although lately, I've seen it happening more frequently. Social Security will send you a notice that you are being reviewed and will ask for updated treatment information and that it is why it is so critical that you maintain an ongoing paper trail of medical treatment, documenting your condition, side affects and why you are unable to work. Try to make sure that you have a treating physician with whom you have a working relationship who can ask, who you can ask, and who would be willing to prepare a narrative summary of your medical condition and how it negatively impacts your ability to work. Ideally, if you continue to be unable to work, Social Security will continue your benefits. If they cease your benefits, you have the right to appeal and if you prove your ongoing disability, the benefits will continue. The good news is, is that the standard for Social Security to prove medical improvement and thus justify taking away benefits is much more stringent and allows far less leeway than the standards for determining an initial claim. Put another way, when somebody comes to me and says Social Security is reviewing my case, assuming that they've done everything that I have recommended previously and they have their records and they are receiving their treatment, most, more often than not, the agency will continue the benefits and I can't do this without occasional war stories. I hung up the phone yesterday with one of my clients who had absolutely zero follow-up post-lung cancer. He didn't go to the doctor at all or at least he didn't go to the oncologist or the

specialist but he did go enough to his treating doctor that it was just sufficient enough for the agency to reestablish his benefits or to continue his benefits.

Overpayment. With the advances in medical science as Shera mentioned earlier and the ever improving options, it's possible that a successful claimant who was "on disability" will get to the day where he or she can return to work. I cannot emphasize this enough. Be clear on the rules for earnings. While on disability, you may earn and work up to just about \$600 per month without triggering scrutiny. This is a number that I use to recommend to my clients. The reason for this \$600 is because the real number is \$720 to \$750. \$720 in 2012 and it's going up to \$750 in 2013. If you earn over that amount in any one month, you are triggering the start of a trial work period. You get accumulative nine months and that's not nine consecutive months, it's nine months. So a month here, three months there, four months somewhere else, you've hit eight months and you're almost at the point where you've exhausted your trial work period. Once you have exhausted any earnings under the, at the trial work months, the next step is substantial gainful activity. At that point, Social Security will look at your earnings and in 2012 the number is \$1,010, in 2013 it's going to be \$1,040. But any month when you exceed earnings of that amount going forward, is going to be a month that you are ineligible for your Social Security benefits. What that means is if you've earned your \$800 a month and blown through the nine month trial work period, great. If you stay at \$800 a month and never go over \$1,000, you're going to be fine, there's not going to be a problem. If on the other hand, you exhaust nine months and the following month you make \$1,100 or \$1,200, unless there are exceptional circumstances, you're eventually going to have an overpayment. If you are overpaid, Social Security rarely catches the error for years and when they finally do, the overpayment is often in the tens of thousands of dollars. If you get one of those notices though, you shouldn't panic. The good news is, is that it is possible to negotiate a payment plan to repay the overpayment. Alternatively and preferable an argument can be made that the overpayment did not happen. Never assume that Social Security's information and calculations are correct. Challenge them and confirm their numbers. I have been successful on these kinds of arguments, essentially it's an argument innumerable times and have been able to get people to continue to receive their disability benefits even as they have been earning what is deemed more than substantial gainful activity. Finally, while it is possible to make an argument for waiver of the overpayment, the rules governing the overpayment waiver make it a very hard sell. It's not something that it's, it's doable, it's very, very case specific.

I hope that this brief overview is helpful. Please don't be disheartened by anything that I've said. If you are in need of disability benefits, file for them or find someone to help you file a claim. You have nothing to lose and enough to gain by sticking with the process to always make it worthwhile. Thank you.

Shera Dubitsky:

Thank you Mr. Herman. I think some of the takeaways from that is that it's important to stay organized, to make sure that you document clearly and really I think the most important takeaway is that you need to advocate for yourself and to continue to do that and to fight for your rights with that. So thank you.

Our next speaker is Ms. Rena Cole. She is the first Vice President of Investments and Wealth Advisor at UBS Financial Services since 2009 and before that, she was the first Vice President with Morgan Stanley for sixteen years. Ms. Cole is licensed for life, accident and health insurance, long term health insurance and annuities. Ms. Cole began this conversation with us about a year and a half ago and I'm glad that

she has really been a significant part of this dialogue throughout the planning of this event. So Ms. Cole, the floor is yours.

#### **IV. Financial Planning Rena Cole, BA, UBS Financial Services**

Thank you. The point, I only have one slide and I think the point of what we want to or what I want to talk about today is try and make this as easy and simple as possible in dealing with your current financial situation because you need to focus your attentions and your strength on much more important things than your brokerage accounts and your saving accounts and all of that.

So I have a couple of logistical things to talk about and then some practical investment ideas that we'll talk about at the end and we'll just go through these bullet points. The first is try and consolidate what you have. Most of our clients and I'm sure most of you who have IRAs in one place, old 401K's somewhere else, savings accounts, checking accounts, brokerage accounts. You're getting statements from five, six, seven different national institutions in many cases. The best thing to do is try and consolidate as much as possible. Some people don't feel comfortable working with one financial institution. That's fine. Try and get it down to two, maximum three. But you need to be able to get your hands on everything that you have and that you know everything that you have. We have clients all the time, two years into a relationship with working with somebody, they come up with a statement of an account that they didn't even know exists any longer from an old job that they had that they'd stop getting a statement from. All of a sudden they were tracked down again. So you don't want to be dealing with any of this. You want to make sure that everything is consolidated and in one place and you can keep track of everything. Nowadays, a lot of people like getting their statements online instead of getting hard copies. Great. Do that but the next part of this is being organized. We use this and I'm going to give this to you guys afterward, they can post it online, we use this for our clients. It's just a personal informational document and it's four or five pages and it just, it gives you highlights and it sort of jogs your memory as to all different accounts that you have and it puts in one place in this one little packet or folder everything that you have with all of the passwords and the ID numbers and you can have all this information yourself. Your spouse, your children, somebody else that you're with, has to be able to have access to all of this information. G-d forbid something happens to you, somebody else needs to be able to have access to these assets. So being organized is of primary importance at this time in everybody's lives. You need to know what you have, you need to know where it is, you need to be able to put into this document or on your own list, who you're contact person is. Your spouse may know that you have an old 401K somewhere but they have no idea how to get in contact with those people. At least a phone number, let alone the name of the benefits person or the HR person. You need to, again, you need to put down your passwords. Don't forget about safety deposit boxes. People forget about this all the time. You cannot be the only signatory on that box. You have to make sure that somebody is a signatory, whether it's your spouse, your sister, your parents, your children who are of age, obviously, but somebody else should have access to all of these things because again, if something happens and you can't get to that box, somebody else has to be able to access all your important papers. So again, being organized is very important.

Another thing that we try to go through with our clients relatively regularly is verifying who the listed beneficiaries are and all of these accounts. Now, in brokerage accounts you do not list beneficiaries for non-IRA accounts. Those are part of your

estate and however your wills designate how your assets should be divided, that's how your regular brokerage accounts, that's what they are a part of. Your IRA's, however, do have listed beneficiaries. You need to make sure that somebody is listed. It should never be your Estate because that throws those assets into your Estate. It puts it into probate and then it's locked up until the Estate is settled. You want to name somebody, a charity, it doesn't matter and you can name fifteen people as beneficiaries but you want to make sure that somebody is listed otherwise those assets get frozen until the Estates are settled. So you want to make sure that all this beneficiary information is updated. You can change it as often as you want and we help clients who do that every time they get into an argument with their children, they do change it and that's fine. They will just use the most recent one that's on file but you just want to make sure that there is a beneficiary listed for all of your assets.

You also want to make sure that you coordinate all of this with your attorney, your accountant and your financial advisor. We have or we try to have relationships with our clients' Estate attorneys and their accountants as well. It's important that everybody is on the same page. It's also important that whoever you are working with in a financial capacity, let alone your physicians, but in a financial capacity, that you have a relationship with them, that you can talk to them about what's going on in your lives because as a financial advisor, we need to know what's going on. We need to know if you're facing a health crisis, if you have somebody in your family that is facing a health crisis that we're going to need to help support them. So hopefully you have that kind of a relationship with whoever you're working with and if you don't then you might be working with the wrong person because honestly, that's the kind of relationship that everybody should have with their advisors. But once you do have that relationship, it's important to hook everybody in together and we'll have conference calls or in-face meetings with the attorneys and the accountants at the same time because we want to make sure we're all on the same page in giving the client the right guidance, to suit whatever they need because everybody is different. So that, I really can't stress that enough that that's a really important point in getting all of your assets together and taking care of all of your financial needs. But it's important that you have that relationship with whoever you're dealing with. I'm not going to say I'm the first call for some of our clients but I like to think that I'm in the top five when something good and when something bad happens. We're getting calls now from clients to help with this hurricane that they need money. They need to rebuild a roof, they need to buy a car. They know they're not going to be reimbursed from insurance anytime soon and you need to be able to talk to the people that you work with.

Very rarely nowadays, but every once in a while, we will find clients who are still holding paper stock certificates and physical bonds. This is not a good idea. They're very cute to hang on the wall. The Disney certificate is adorable. It has all the characters but it's so difficult if something happens to the person that owns that certificate, it is very difficult to get everything in order. The easiest thing to do is to deposit those certificates with a financial institution. It doesn't cost anything. It shouldn't cost you anything. They will send you statements every month, they'll reinvest dividends if that's how you've had it all along. They'll pay out the dividends if that is what you want but owning those physical stock certificates or the physical bonds, it's just gives everybody else a headache when you're not around to deal with it. So again I would urge you, make sure that you deposit those physical certificates somewhere and take care of them.

Another area, before we get to the specifics of how you might want to be investing, is you might want to be looking to maximize credit at this time. I'm not saying to max out

your credit cards. But because liquidity is an issue and you may need access to cash, you might be looking to refinance your house. With the interest rates where they are right now, that could free up an extra couple of dollars a month for you by getting a lower rate. Consolidating credit cards. Depending on what your situation is, you may qualify to take a loan or a distribution from your 401K. Again there are parameters that you have to fall within in order to be able to do that but it is a time to be looking to maximize those credit relationships in order to get a little more liquidity and increase your cash.

That brings us to more of the specifics of how to invest. I'm not going to give specific stock recommendations obviously. I think the key is liquidity, is paramount. Everybody is facing a point in their lives where you don't know what's going to be. You don't know what's going to be three months from now, six months, six years from now. There is no way you can be investing your funds under that umbrella. It's impossible. You don't know whether you're going to need to access these funds and you don't know how much your insurance is going to cover. The liquidity needs for everybody are different. If you have a fantastic insurance policy, you may never need to touch savings. If you thought you had a fantastic insurance policy and it turns out you don't, you may need \$50,000 next month. So being liquid is important, it's of utmost importance. Making sure that you are not stuck in volatile investments is again extremely important. I'm not saying that you go out tomorrow and you call your financial advisor and you sell everything you have. I am not saying that at all. However you do need to have a conversation because the worst thing that can happen is a day like today, the market was down 300 points and you call your advisor and you say I need to sell \$150,000 worth of stock. I need this for experimental treatment, whatever it is. You never want to have to sell anything immediately because you don't know what the market is going to be doing or where that investment is and how it's been performing. The worst thing that you can possibly do is be forced to sell something. The best thing to do is to make sure that you have that liquidity and access to your funds without having to do that. It doesn't necessarily mean putting everything into cash, earning you nothing right now. It does mean that you need to make sure that you have a steady stream of income, that you are in low volatility investments and that you don't have to be forced to lose sleep at night because you don't have money in the bank to take a cab to the doctor the next day. So the liquidity is paramount and the low volatility is extremely important.

That's really all I wanted to touch upon. I don't really want to get into long, drawn out specifics of types of investments. I'm happy to talk about this later. I will just share, I have a very long term client who got a bad diagnosis and spent a lot of time planning for what she thought was going to be just the next couple of months and thank G-d, the end never came for her and she's healthy and she's doing great but that time that she spent planning and making all these changes and getting all of her papers together and planning for what she thought was going to be a bad ending for her, it makes her life now so much easier. So she appreciates what she had to go through in making all of these plans because now she doesn't have to worry about these things. I read a story, somebody was quoting a gentleman who went through this and he said he was viewing this as his love letter to his family, making all these plans and doing the wills and the trusts and all of that, making it easy for everybody when he wasn't going to be around, to deal with all this. So hopefully nobody will have to look at it like that but it's just to be. Nobody wants to be thinking about these things and that's why I say, make it as easy as possible so you deal with this for a couple of weeks and you don't have to be thinking about these things and can worry about all the other important things that everybody is facing.

Shera Dubitsky:

Great. Thank you, Ms. Cole. I want to highlight something that you just said because we do receive a lot of phone calls from women who are overwhelmed by this and they don't want to approach it and they don't want to have these conversations with their family and with their spouses and so I think that your point in terms of dealing with it and managing it so that you can get it off your plate and it's one less thing to worry about, is very important. So thank you for that.

Our next speaker is Ms. Jodi Scherl and she is also joining us over a phone this evening and she advises clients on estate and trust planning, estate administration, special needs planning and elder and Medicaid planning. She has a solo boutique practice in Tenafly, New Jersey since 2007. Ms. Scherl is a frequent lecturer to parent groups of special needs children and has taught continuing legal education seminars in various areas of her practice and Ms. Scherl was also part of this discussion a year and a half ago and so we are very happy that she was able to join us and agreed to participate in this event even though she is over the phone. So we are very grateful for Ms. Scherl for that and with that, I'm going to hand the floor over to you and if you can just tell me that you want me move along with the slides.

**V. Estate Planning**  
**Jodi Scherl, Esq, Law Office of Jodi B. Scherl LLC**

Okay, good evening everybody and I do apologize that I'm on the telephone. It just became a little impossible with the weather to get there. So you'll forgive this, it's not nearly the personal touch that I prefer but nonetheless, it is what it is. So here, I just want to take you back actually on what was just said because it really is the first question I'm asked. What is the first step in the estate planning process? And that is exactly what we've just been discussing. The first step in the estate planning process is to be forceful about what needs to happen next. What makes this process easier? What makes this process more organized? It's simply addressing the fact that you need to have a process and that the hardest part about beginning this process is simply beginning it. But once you do that, everyone will probably be able to attest to the fact that once they do that, that's the worst part of it. It's just addressing the fact that you need to become a little more focused because the moment you do that, you can breathe. There's like a release and that's one less thing that you thought maybe you didn't have control over but in fact, it's not such a bad process. It's an easy process. You just have to hand it over.

So once you do that, I guess we're at number two, what documents are necessary to building blocks? I like to call the last will and testament, a power of attorney, and healthcare document my building blocks because those documents are the three most important documents for anybody. What they say is one thing but we know we need them. How complex they become is irrelevant but we know we need them. So the first step is to just make sure that assets, no assets, children, no children, spouse, no spouse, is healthy. Every single person needs the building blocks.

So number three was the last will and testament. How does the will become effective? So the last will and testament is number one of the building blocks. It is a testamentary document, meaning one that explains our wishes once we have passed away and it states our wishes and puts somebody in charge of administrative wishes. And the will becomes effective by saying what you want in a written document and then having that document properly executed in accordance with a particular state. Every state in the United States requires at least two witnesses to a last will and testament and a notary public that the testator, who is the person making a will, has the capacity to make that will and capacity is a relatively broad topic, one that

generally means that they understand and that they are making a will and they understand that they're putting their assets in somebody else's hands. Meaning, they're understanding who the objects of their bounty are. That's the technical legal term. Who are the people getting the bearer's assets? Who are the people who are in charge of this document when somebody dies? And so as long as you understand that and those are basics, then your will can become effective and this will can be as simple or as complex depending upon your circumstance. So, for example, if I do not have many assets and do not have children or have children who are not minors, who are under eighteen or even under twenty one for both states for reasons that are not so relevant. When you have young children the circumstances become more complex. So when you have adult children and perhaps a spouse, your will can be very basic and very easy and those might change as you become more wealthy, as you are married or as your children are minors because we might need to have more beneficiaries under our will, meaning the people who inherit things. We might need to protect those assets for the sake of a child and I'm going to talk about that in just a moment and those would be using trusts. We might have assets that are something we have to protect as far as the tax structure goes. So at the end of the day, a will can be complex or basic depending on the value of that estate and the people who might inherit that estate.

So a moment ago we talked about how does a will become effective. We talked about witnesses and a notary but now can I hand write a will because we not only have people that want to document their wishes in writing, handwriting, but also I found that clients often take a will that exists already and they circle little notes or changes, maybe it's because that's what they want to happen ultimately or maybe it's because that's what they expect to tell the lawyer when they get around to it, how they want to change the will that exists. In any event, that handwriting, which is known legally as a holographic writing, that means that the question is how effective and legal are those writings. If somebody passes away without finishing the job, without saying to a lawyer make the changes and then I'm going to sign them or doesn't even think to tell a lawyer, doesn't even attempts, just thinks they're doing the change on their own. So what does that, what does a handwriting do in this circumstance? Well, if the handwriting exists and it's found either on the original document or with the original document, then that handwriting may be effective if it's signed by the testator, again the person who makes the will, and it is dated. So if we find a handwriting signed and dated, we may very well have an additional document that we need to deal with when we go to either probate a will and handle the administration of some of the estate. Having said that, really the last thing we ever want is a holographic or handwriting. We always want to think that when we've spoken to and come before you at any point in the estate planning process, that you're very careful not to allow these kinds of things to become your plan. Because, again, back to organization, an execution of the plan, handwriting will create a lot of aggravation. Do we have a handwriting, is it legal? Is it able to be probated the same way? All the answers to these questions are - nothing is the same. The probate is not the same, the process for time is not the same. It will be a much more lengthy process and finally, the cost to probate a handwriting can be exorbitant comparatively. So when we talk about making a will, writing down some wishes, we want to make very sure that we do so in a way that involves a visit to your attorney and involves formal execution of the document that expresses all of your wishes. And that can change over time. You can do an amendment to a will called a codicil. There are a lot of ways to do things without even rewriting the entire Will but at the end of the day a handwriting is a last resort and it's not the most reliable and again the cost is really now a very practical option. So you want to be just really careful when you

are considering these kinds of changes or comments on your will but that you do so formally.

I think that I've touched on number six with this option to change my will. When my clients are creating documents, one of the things that I try to express to them very sincerely is that I'm not asking you to make a decision about every single thing this second that's going to last forever. We have to think of every contingency and you need to be concerned about the "what if". Now, granted, my job is to be concerned with the "what if". That's my job, to make sure we've covered all of our bases. But at the same time, it's impractical to think that you will be able to plan for all the "what ifs" and that, it's best to get something in the document rather than nothing because you're unable to make a decision at the moment. So for example, a very good example of this that I find my clients have the most difficulty with is, I have children and I need to place in a will who is their guardian should something happen to me. And that involves very stressful thinking and it's a tough decision to come to. And oftentimes my clients say to themselves who will be the same parent as I am and of course the answer is nobody. So what the attorney's job is to move you through making a decision about that so that you can in fact execute documents that are so critical to order and at the same time, understanding that these don't have to be all permanent decisions. That, G-d willing, we have time. Six months down the road, I very much may change my mind and changing your mind is perfectly fine. All you have to do is do a simple codicil that's a paragraph long. The only thing these codicils must make sure that they do, and again a codicil is a change or an amendment to a will, is follow the exact same testamentary formalities and that again is witnesses and notary public and signatures. If the codicil follows those exact formalities, then it will become an additional document that becomes part of the will and you may change that as many times as you want throughout your lifetime and people that are healthy, people that are not healthy, they change their documents all the time. These documents are able to be changed with ease. The necessary important thing to understand is that once you make these decisions, and sometimes it's a matter of just closing your eyes and making the best decision you can at that moment, so that a decision is made because the alternative is complete disorder and that's not a good alternative for both people.

So what are the next? How do I protect my children? Well this gets back to why we do a last will and testament. One of the most important things is making sure that the document is effective. And once we do that, the question is how do I make sure that my children are protected? A lot of that will depend upon their age but discussion will really be the same. Regardless of age, it will be critical to determine whether or not they're responsible enough to inherit money outright. That's really the question. What happens when they get money in their pockets? That it's theirs to keep and to do with as they please. Are they responsible? Do they have stable marriages? There are no sure things but sometimes you know that when you make a document and you might say, I can't guarantee that. I do not want my assets to go to my child and ultimately be part of a discussion in a marital dispute. Are my children involved in activities that are not my favorite? Do I have to be concerned about that? Are my children fantastic perfect beings but they do tend to spend a little money irresponsibly? All of these questions are important ones to have and they may require that a Trust be established for their benefit, one that protects against creditors, one that protects against spouses, one that protects them against themselves and one that just protects them because they're just too young to inherit money in the first place. So these discussions are very critical to have but not so difficult to resolve once the discussion is passed. And that kind of leads into slide 8 about trusts. When we talk about that, we are talking about should the trust just be until they're thirty, until they're

old enough to make their own decisions? Do I have such significant assets that a lifetime trust is appropriate? Do my children have special needs that I need to be aware of and therefore I need to protect them as well? So all of these questions need to take place and the answers reveal themselves to their attorney as to what is appropriate as far as your plan and certainly what is appropriate with respect to asking the questions.

Shera Dubitsky: Ms. Scherl, we have about two minutes left.

Jodi Scherl: So sorry, I'm going to go to health care documents and power of attorney then. I'm sorry, I felt that I lost track of time a little bit. It's hard when you're virtual to figure out what's going on. So that power of attorney and healthcare documents really are the most important thing. Frankly, I think that in a sense if I realize that I would be limited, should have begun with them because they are the living documents, the documents that operate when somebody becomes unable to make their own decisions, either through legal or financial reasons or health related decisions and these documents are the most critical. If you never make a will, if you never do much with an attorney, my suggestion is that these documents are very, very useful and of course the most inexpensive because they're almost all forms. So I urge you to make sure you've got those documents. Healthcare documents, the words living will, I remember that being a question is a term for almost something in the event of neurological death, a very terminal condition that is unable to change, those are all important documents.

But the healthcare proxy which is in addition to a living will, is something that absolutely is a necessity because that appoints a healthcare representative to coordinate with physicians, hospitals, banks, records of your health, and make decisions in case you can't, to decline treatment, to accept treatment, to choose between treatments and procedures. So this is the most critical document. It's not the form that you sign in a hospital. It shouldn't be. That form is way too basic. This form should consider HIPAA, which is the federal healthcare act that relates to privacy and again finally, your powers of attorney, who's going to take care of your basic financial concerns as far as paying bills, making financial investments, if necessary, changing ownership of things, etc. This power of attorney is a critical document. Both of these documents appoint a representative for you as an agent to serve in your place and I guess if I had no more time, I would have to conclude about there's so much more. I apologize that I didn't get to all my material.

Shera Dubitsky: Well, thank you and I think that again, the theme of the evening is that all the topics that we're discussing tonight seem overwhelming and we hear that a lot from the women and I guess the message is to start the process because once you start the process, then I think you can go ahead and establish these building blocks that Ms. Scherl was discussing. We're going to conclude our panel discussion tonight with Michelle Shagenov. Michelle represents the many women of Sharsheret who are concerned about the financial wellbeing once diagnosed and this is something that Michelle and I discussed when she was diagnosed and what was most impressive to me was her doing just that, her starting the process and her being pro-active in securing her financial health. So Ms. Shagenov, I'm going to ask you to share briefly some of your experiences and some of your takeaways.

## **VI. My Journey to Financial Health Michelle Shagenov, Sharsheret Peer Supporter**

Good evening everyone. I hope by sharing my story about the financial assistance application process, it becomes a little less daunting. As Shera said, I'm a breast

cancer survivor. I'm now almost two years out from treatment. Thank you. Thank you. Thank you very much. So pre-cancer, unfortunately I'm not independently wealthy. We work. I was working part-time three to four days a week. I kind of rotated dealing with just day to day expenses, student loans, mortgage. I had a young baby so I was also dealing with childcare and just trying to make ends meet. And basically, doing okay. And then I was diagnosed with breast cancer at 27. My son was 16 months old when I was diagnosed and that's when things really changed making ends meet, really took a turn for the worst. My treatment involved two surgeries, four months of chemo, five weeks of radiation. Anyone who has had a health crisis knows it's exhausting. I was sick, tired, that affected my ability to work as I was only working a few days a week and the loss of income wound up, we wound up with financial difficulties. That was a big problem because we had to pay those hospital bills somehow.

So I'm going to get into how exactly we dealt with the mounting hospital debt. So my first step was reaching out to family and friends for whatever we could get from family and friends, rides to treatments, friends gave us a fresh start, gift cards, we had help from friends of friends with watching my son while I was in treatment and just not feeling up to watching him. I would also say utilize whatever available resources you have. I have a friend who happened to be a social worker. I talked with her about my situation. She referred me to one non-profit organization and she also contacted a Sloan Kettering social worker where I was treated to ask about financial assistance programs that were available there. I spoke to the social worker at the hospital where I was treated at Sloan and I was referred to two financial assistance programs that they have. One was medical financial assistance program which helped with the hospital bills and the other was a non-medical financial systems program for things like parking, childcare, so on and so forth.

That was very helpful but that wasn't enough unfortunately and so I was referred to the two major not-for-profits that deal with cancer patients that everyone is probably very familiar with, American Cancer Society and Cancer Care. Unfortunately, I did not meet their eligibility requirements for Cancer Care Co-Payment Assistance program. I just earned too much money and American Cancer Society, similar issue. Also they do not have Road To Recovery in New York City. That's a program where cancer patients have rides to treatment. They also do not reimburse for gas mileage if you live, what they deem close enough to the hospital. So that's what I call my, I'll just try my luck point. I got desperate. I have to pay the bills. The hospital bills were coming and I figured I will just try my luck and go online and search Google and search terms "cancer financial assistance", "breast cancer financial assistance" and see what comes up. And that actually did work out quite well for us through small non-for-profit organizations that you don't hear so much about. We were actually able to break even and pay off all the medical bills. So some of, I guess, the general tips that I learned along the way is your community is your first step and your best resource for help and information. Start with family, friends, your religious community, organizations. First of all they can all pitch in with money, food, childcare, chores and just ideas of where to go next.

When applying, pay really close attention to the eligibility requirements. They are different for every organization. I would say maximize efficiency. A lot of the applications ask for the same things over and over and over again. Just get everything in one shot as much as possible. Time is of the essence when you are in a health crisis. Energy is in short supply. There are things that you can really get in one shot like doctor's notes, almost every single financial assistance asks for those or breast cancer financial assistance, biopsy scan. Just have those, have a bunch of

copies of those. Don't rely on your memory. This was something that I, a mistake that I made at work when I was going for treatment. I'm an estate attorney and good company with the attorneys here and I thought, "Oh, I have a photographic memory and I can just remember everything". And I found that wasn't working so well for me. I just didn't have the concentration and focus that I had pre-treatment and I had to start to keeping detailed lists to stay organized. So keep lists, applications often have deadlines and you want to stay on top of those. It's been said by a few of the prior presenters, stay organized, really stay organized. Keep everything in one place, that will make things much easier. I would also say, have an open mind and apply to multiple organizations at one time. Kind of treat it as a college application process. I know that sounds funny but you really don't lose anything by applying to an organization. The worst thing that's going to happen is that you're not going to hear back or there's going to be a long waiting period. You really lose nothing by applying even if something is in a different state or it's an organization that you haven't heard of before.

And also something to keep in mind is one organization is probably not going to be able to meet your entire financial need. A lot of the organizations that we received help from were really small non-for-profits that were donation funded, volunteer run, just had a very small budget of what they were able to provide us with. So it took kind of piecing together several organizations and several types of assistance to be able to get through that time. And I would also say be creative and think outside the box. Every little bit helps and there are different kinds of assistance. They're not just financial assistance grants, there's co-payment assistance, prescription assistance, some organizations provide meals, some organizations provide assistance with childcare or household chores or just brightening up a difficult time. There are quite a few organizations that have pampering services or free vacations which is if you don't have the extra income for when you're going through a health crisis but you need a mental health break as well. I would also suggest tag teaming if some, the person going through the health crisis is not so great in handling forms or is not so nuts about numbers. One person does the forms, maybe a friend, a spouse, somebody else handles a different part. That was our situation. I hate numbers. I hate math. I told my husband I will find the applications. I will find the organizations that I can apply for. Please handle the finance part. Give me all the numbers. I'll put them in. Don't make me look at them. That's it. And that's all. If there are any questions.

Shera Dubitsky: Thank you. Michelle, you're really serving as a peer support to hundreds of women who are going to listen to your tips tonight. So thank you for sharing your experiences and takeaways. I just want to say that there are many organizations in the Jewish community that do offer financial aid so that's something that you can certainly look on Sharsheret's website or give us a call and we can give you that information.

## VII. Question & Answer Session

Shera Dubitsky: I'd like to now pose some questions to our panel. Questions that we received prior to the event and I guess we'll start with you, Ms. Morales. The question is, how do I learn about co-pay assistance from pharmaceutical companies?

Joanna Morales, Esq: The fastest way to find out is if you know what drug you're being prescribed or what drug you are taking, is to find out who the maker of those drugs are and when you find out who makes the drug, actually go to their website and look for pharmaceutical assistance programs. There are also two other ways that you can find out this information across the board instead of for a specific company. You can go to NCI's website, the National Cancer Institute at Cancer.gov and they have a new search tool

for financial assistance including prescription drug. And then there is also the cancer support community has a guide called “Frankly Speaking, Coping with the Cost of Care” and in the back of that guide is a list about all the pharmaceutical companies and the contact information for their pharmaceutical assistance programs. And then Google is also a fantastic tool.

Shera Dubitsky: Thank you. Another question for you, Ms. Morales, is how does one communicate with their doctor’s office when there’s a delay in payment from the insurance company and will some doctors waive their fees?

Joanna Morales, Esq: I think the best way to handle communication with your provider is to communicate. So a lot of people don’t actually let their doctor know what’s going on in terms of payment or their provider. You should actually have an open dialogue. So if an insurance is taking a long time to process a payment, your provider can also be resources in that regard and they can call your insurance company to follow up and see what’s going on with a particular payment that you haven’t gotten and need a response back. Because there’s human error involved and if sometimes you panic, it can be challenging. So maybe someone miscoded something on your bill or sent the bill to the wrong fax number or things can happen. So it is a good idea to stay on top of it and to pay attention to what’s going on and keep open lines of communication with your provider. And then tell me again the second part of the question.

Shera Dubitsky: Are there times when the doctors will waive their fees?

Joanna Morales, Esq: If you find yourself in a circumstance where your insurance company has only paid a portion of your bill or you don’t have insurance coverage or for some reason you can’t pay part of your bill, a lot of healthcare providers will negotiate with you. So they’ll either, you can ask them to potentially reduce the bill or to write off a portion of your bill, and then in a worst case scenario they say “no” and they’re not willing to work that out with you, they may be willing to negotiate a payment plan. So if you maybe have a \$10,000 bill, there’s no way you can pay that \$10,000 immediately but maybe they would be willing to let you pay \$100 a month for an extended period of time so that you can pay them that bill. But even large hospitals and small providers are willing to negotiate payment plans because they rather have some money than no money and try to go after you and collect.

Shera Dubitsky: Thank you. Mr. Hermann, can you get disability insurance after diagnosis?

Gabe Hermann, Esq: Disability insurance is, well, disability insurance isn’t actually my field. With regards to receiving Social Security disability, obviously you need the diagnosis. In my experience with long term disability carriers, that would probably be one of the things that they would look at in underwriting and making a determination on whether or not the disability is something that they want to cover. If you do, however, file and set up an insurance, more often than not they will grant the disability but they will pretty much carve out whatever your present diagnosis is, any potential future diagnosis that you might have as a result of this diagnosis so that if your diagnosis is breast cancer, ovarian cancer, lung cancer or whatever kind of cancer, they’ll say, if you hurt your back, you can get disability for that but you’re not going to get it for this and it’s not likely that even exorbitant premiums will get you the disability for a condition assuming they’re willing to underwrite it.

Shera Dubitsky: And is there a difference between qualifying for short term versus long term disability?

Gabe Hermann, Esq: Yes, short term disability is a program which is usually offered through the states. I know that in my experience, in New York and New Jersey, if you look at your pay stubs, there is a deduction that's taken for short term disability. Some companies will handle the short term disability through an insurance company. So your employer will go with a Unum or a Northwestern Mutual or any of the larger insurance companies and they administer the short term disability. Sometimes, they'll then also administer any long term disability benefits which are also private paid policies. If you don't have it through your job, obviously the short term disability, it's virtually mandated. It's honest monies, a few hundred dollars a week. But there are employers that bump that up, that supplement it and there are employers that for the first six months of a condition, might even pay your salary, take back whatever the disability amount is that is paid out and just pay you the balance. But those are very, very fact in case and employer specific.

Shera Dubitsky: Okay and the last questions we have for you, Mr. Hermann, is how do you qualify for disability if you have private insurance?

Gabe Hermann, Esq: You're talking about long term disability.

Shera Dubitsky: Uh huh.

Gabe Hermann, Esq: Long term disability, assuming that you have it, you have it through a job and something that I omitted is if you go to a job with a diagnosis or rather you're employed by somebody and have been previously diagnosed because it's a group plan, everything I said before probably doesn't apply which is great news. It means that if you go someplace, they can't pull you out and identify you and say no, you can't get insurance because you had cancer and now you're trying to go out on disability again because of cancer. They will try but usually that is something that can be overcome just by the policy, the way it's written. But the, sorry I forgot the question.

Shera Dubitsky: How do you qualify for disability if you already have private insurance?

Gabe Hermann, Esq: Okay. So in order to receive long term disability, you file. In order to receive Social Security disability, you file. Most policies now, in order to save money on the hit, on the financial obligation of paying out, have a paragraph saying, if you are eligible for any kind of state administered disability or retirement or workers compensation or railroad or Canadian insurance or any government insurance benefit, they get dibs on it. That means they take it. So if your monthly benefit from a long term disability carrier is \$5,000 and Social Security, you're monthly PIA, the index benefit that you're eligible for is \$1,200. In a case like that, the insurance company is going to say, well Social Security is giving you your \$1,200 and of the \$5,000, you're going to get \$3,800 of that. The end of it, you're still there with \$5,000 so it's not a terrible thing.

I'd be remiss if I didn't mention this and this is very important to anybody that is considering representation, is receiving long term disability and wants to file for Social Security disability. Number one, they make you file and the insurance company, not only do they make you, but they subtly encourage you to use their representatives. They have contracts with these representatives in order to pay less for the disability, the payout to an attorney or representative. The thing that you have to remember is that these insurance companies and the firms, the organizations, the advocacy groups that they are utilizing, they may say that there's a wall, they may say that there's a separation between what long term disability insurance carrier is providing and not what they know and what these people know for disability. It's not

there. They will be tripping over themselves to give the information to their, essentially their employer. So if you ever find yourself in the situation where you are receiving long term disability, you are obligated to file for Social Security, find somebody else to represent you. They're not going to make you use the Unum, the Alsop or the dozens at this point national companies that do this. Use somebody local, whether it's somebody in your state or somebody in your geographic region but somebody that knows the local offices, knows the judges and at the end of the day, when you win your case with Social Security and the insurance company knocks on the door and says please pay us back, they will deduct whatever your attorney charges you in order to get that amount. So if your attorney charges \$1,000, \$2,000, \$5,000, whatever the amount is, and you receive a lump sum check of \$30,000 from Social Security, you don't owe \$30,000 to the insurance company, you only owe \$25,000 which essentially means that you have nothing to lose by using an attorney, a local attorney or somebody that's of your choosing. And my personal experience is when the insurance company, Northwestern or whoever contacts me and asks for the information for my client, I don't really trip over myself to give them that information, particularly because sometimes the information that I have in my possession is not going to help the case and is certainly not going to help them when they do their invariable and frequent review of the case. I don't have an obligation. I view it as work product.

Shera Dubitsky: Thank you. Ms. Cole, when thinking about financial planning, what are the most important documents to keep in your file?

Rena Cole, BA: I think when you need to keep your, when you're trying to get all of your papers together, is that what you mean what's most important? I think to be able to, as I mentioned before, have the contact information for where all of your accounts are and who you are working with because then if you're missing anything, you'll be able to contact those organizations directly and they can get you any statements or account information that you may not have. But otherwise, to track any of your accounts anywhere, all they need basically is your date of birth and Social Security number and they'll verify it over the phone and your home address. But I think really the most important thing is to have a list of all of your accounts, where they're held, who you're working with and those account numbers and have all that in one place and then it's easy to track everything.

Shera Dubitsky: Thanks you. Also, are there ways to set aside monies to accumulate savings during this financial stress?

Rena Cole, BA: I think during, while you're going through a health crisis, I think it's very difficult to be setting any funds aside. If you're still working and you can still afford to be contributing to your 401K, that's obviously the right thing to do. That's money that hopefully you're never going to touch but making active savings while you're going through a health crises, I think can be very difficult. What we always try to have our clients do is to make sure that they're saving before any of this happens. So you're not hit with something and scrambling to make sure that you have enough to pay your bills. That's always the best, being pro-active before anything happens, it's always the best thing and setting up regular savings plans, again, through your retirement accounts, after-tax savings, automated savings plans. Those are always the best things to do but I think it would be very difficult while you're going through the crisis to be setting aside regular funds.

Shera Dubitsky: Thank you. And we only have time for one last question and that is going to go to Ms. Scherl. The woman asked if she should think about divesting in her money if she's

living with a chronic illness. Will that help in her being able to get financial assistance if she has fewer assets?

Jodi Scherl, Esq: Okay. You know having financial assistance, I assume we need be financial assistance that would be available to somebody who really has depleted their assets significantly if not completely. That's a very difficult question to answer because it really depends on a million things. The reality is that Medicaid assistance or SSI that we touched on earlier, these kind of need-based government programs that pick up basic care needs and residential care needs, are so unique. I don't know really that that would be applicable to your, again there are many government subsidies out there for people with disabilities but I don't really know specifically what the circumstances are. It's very difficult to speak to that globally. I apologize but I don't know if anybody else thinks differently.

Shera Dubitsky: Mr. Herman, can you address it.

Gabe Hermann, Esq: Very briefly, in Social Security, in Supplemental Security Income, the Social Security administration will look at your assets. If you have divested them legitimately and this is from my experience, it's not a black, it's obviously not black letter or explicit law on this but in my experiences, if somebody has assets and they legitimately divest them, they pay back family, they separate themselves from the money for medical bills or expenses or whatever what have you like that and then they need to file for supplemental Social Security Income or are otherwise eligible for Medicaid, then there is less likelihood of a look back period or the look back is, well yeah, you spent your money legitimately. Typically though, if somebody is just moving the money to somebody else so that it's not in their account, if it was in the account last month and it's not in the account this month, Social Security is going to wonder where it went and in cases like that, there will be a look back period. Having said that, I know there are organizations and there are companies that have mastered the art of divesting of assets and resources to make people eligible for Medicaid and SSI. I imagine that they are legitimate. I have no opinion about them. I don't use them and I don't really make recommendations to people on that issue. In truth, though, for the most part, when somebody comes to me eligible for Supplemental Social Security Income, it's because they have already exhausted their assets legitimately. Yeah, on that note, having bent down, the concept of divesting really the people's term for divesting, again unless you need residential services, the SSI, the Social Security Income, it's really not going to resolve the problem. It's really a last resort here. This is not something that's going to provide you with the answer, I don't think. That's why the question is not necessarily one that will solve the problem or help significantly in residential care.

Shera Dubitsky: Michelle, I'm sorry, one last question, after having filled out all these financial assistance applications, any tips?

Michelle Shagenov: Unfortunately there are really, there aren't so much shortcuts. I would say a lot of the financial assistance applications ask for the same information, monthly income and expenses. As I had said before, doctors' notes, biopsies, scans, thinks like that. So if you kind of have a sample application handy if you will, that really speeds up the process with completing other applications.

## **VIII. Roundtable Discussion Conclusion Closing Remarks**

Shera Dubitsky:

Great. Thank you. I want to thank our panelists for really being able to lay out such a complicated issue. This evening began with us hearing from the women calling into Sharsheret and listening to their concerns about financial health. So, our journey continued obviously with the focus groups and with tonight's discussion. Our next step is to develop a tool kit for women to use in navigating the healthcare and financial systems and a transcript of tonight's discussion will be included in the kit. We will also be enhancing our online resources on Sharsheret's website, providing additional information and links to relevant organization.

I would like to remind you to please complete the evaluations. As I said earlier, all of our programs are driven and enhanced by the feedback that we receive from you. We would like to continue this dialogue with you, so stay connected with us. You can reach us at our office at 866.474.2774 and you can visit our website at [www.sharsheret.org](http://www.sharsheret.org). Follow us on Facebook and on Twitter.

I really want to thank all of you for participating in tonight's conversation. To our experts, to the women who have been talking with us about this issue, and for those of you who are joining us this evening both in person and on live stream, we are looking forward to continuing this mission to better understand what action can be taken to improve financial help and to help us feel more empowered as we all confront these challenges. So thank you.

## IX. Speakers Bios

**Shera Dubitsky, MEd, MA** is the Clinical Supervisor at Sharsheret. Shera assists women newly diagnosed and at high risk of developing breast cancer, provides supportive counseling to women living with metastatic breast cancer, and lectures nationally on topics addressing the needs of women facing serious illness. Prior to joining the Sharsheret staff, Shera worked as a researcher at Memorial Sloan-Kettering Cancer Center.

**Joanna Morales, Esq.** is a cancer rights attorney, author, speaker, and Chief Executive Officer of Navigating Cancer Survivorship, a national nonprofit organization connecting people to cancer survivorship resources. She also serves as Principal of North Star Alliances, a business and nonprofit consulting and service firm. Mrs. Morales has spent eighteen years working on behalf of individuals with cancer, including twelve years at the Cancer Legal Resource Center, five years as an Adjunct Professor of Law at Loyola Law School, teaching a seminar in Cancer Rights Law, and eight years working at the John Wayne Cancer Institute for its Psychosocial Care Program and Positive Appearance Center. Mrs. Morales has presented hundreds of educational seminars throughout the country for patients, survivors, caregivers, health care professionals, advocates, lawyers, employers, and the general public. In addition, Mrs. Morales serves on numerous cancer community committees and boards, including the Board of Directors for the California Division of the American Cancer Society, as Chair of the California Dialogue on Cancer's Advocacy Team, and the National Advisory Board of CancerForward. She has been published in a variety of publications, such as *Psycho-Oncology*, *Coping with Cancer*, *Women*, and *Ability Magazine*. In 2009, she also contributed to a book entitled, "Work and Cancer Survivors." Mrs. Morales has received numerous awards and recognition for her service to the cancer community and her work in the area of legislative advocacy, such as the 2009 Susan G. Komen for the Cure® Public Policy Advocate of the Year. She was also recognized by the Los Angeles Daily Journal as one of the Top 20 Attorneys in California Under the Age of 40 in 2010.

**Rena Cole, BA**, is the First Vice President-Investments and Wealth Advisor at UBS Financial Services since 2009. Before that, Ms. Cole was a First Vice President with Morgan Stanley for 16 years. Ms. Cole is FINRA registered with series 7 and 63 securities licenses as well as licenses for life, accident and health insurance, long-term care insurance and annuities.

**Jodi B. Scherl, Esq.** advises clients on estate and trust planning, estate administration, special needs planning, and elder and Medicaid planning. She has a solo boutique practice in Tenafly, New Jersey since 2007. Ms. Scherl is a frequent lecturer to parent groups of special needs children, and has taught continuing legal education seminars in various areas of her practice. Prior to opening her law firm, Ms. Scherl was Of Counsel to Cohn Lifland Pearlman Herrmann & Knopf, LLP, where she spent nine years heading up the tax and estate planning and elder law departments. During that period of time, Ms. Scherl taught as an adjunct professor at Fairleigh Dickinson University.

**Gabe Hermann, Esq.** is a lawyer with offices in Elmsford, New York, and Hackensack, New Jersey. After several years as a prosecutor, Gabe began practicing Disability Law in 1997, and has successfully represented thousands of disabled claimants since that time. Gabe has lectured often to both legal groups and disability-related organizations.

## X. About Sharsheret

Sharsheret, is a national not-for-profit organization supporting young women and their families, of all Jewish backgrounds, facing breast cancer at every stage—before, during, and after diagnosis. Our mission is to offer a community of support to women diagnosed with breast cancer or at increased genetic risk, by fostering culturally-relevant individualized connections with networks of peers, health professionals, and related resources.

Since Sharsheret's founding in 2001, we have responded to more than 25,000 cancer inquiries, involved more than 1,650 peer supporters, and presented over 250 educational programs nationwide. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life. **All Sharsheret's programs are open to all women and men and Sharsheret is the beneficiary of funding from the federal government.**

Sharsheret offers the following national programs:

### The Link Program

- *Peer Support Network*, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- *Embrace*, supporting women living with advanced breast cancer
- *Genetics for Life*, addressing hereditary breast and ovarian cancer
- *Busy Box*, for young parents facing breast cancer
- *Best Face Forward*, addressing the cosmetic side effects of treatment
- *Family Focus*, providing resources and support for caregivers and family members

- *Ovarian Cancer Program*, tailored resources and support for young women and families facing ovarian cancer
- *Sharsheret Supports*, developing local support groups and programs
- *Thriving Again*, providing individualized support, education, and survivorship plans for young breast cancer survivors

#### **Education and Outreach Programs**

- *Health Care Symposia*, on issues unique to younger women facing breast cancer
- *Sharsheret on Campus*, outreach and education to students on campus
- *Sharsheret Educational Resource Booklet Series*, culturally-relevant publications for women and their families and healthcare professionals

## **XI. Disclaimer**

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care professional. The document does not recommend the self-management of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

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