



Thanks to the support of the Washington Square Health Foundation, Gilda's Club Chicago was honored to bring Dr. Jessie Gruman to Chicago as the keynote speaker for its *2010 Corporate and Foundation Breakfast*. Dr. Gruman is the Founder and President of the Washington, D.C.-based Center for the Advancement of Health. She is a member of the IOM committee responsible for the landmark report, *Cancer Care for the Whole Patient*, which recommends a standard of care for cancer patients. Dr. Gruman is also the author of *AfterShock: What to Do When the Doctor Gives You – or Someone You Love – a Devastating Diagnosis* and a three-time cancer survivor.

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## **What It Takes to Benefit from Cancer Treatment** **Jessie Gruman** **Center for Advancing Health**

**May 25, 2010**  
**2010 Corporate and Foundation Breakfast**  
**Gilda's Club Chicago**  
**Chicago, IL**

I am here today wearing three hats:

First, as a cancer patient. I have been diagnosed with three different kinds of cancer and like many of you, I deal daily with both the aftermath of my diseases and the long-term effects of those highly intrusive and aggressive treatments. And, like all of you, I am deeply grateful for those treatments and clinicians whose efforts make it possible for me to be here today.

Second, I'm here as the President of the Center for Advancing Health. The Center is an independent nonpartisan organization in DC that's supported by foundations and individuals. Our mission is to ensure that every person is prepared to participate fully and competently in their health care. We advocate for support of psychosocial research about and the implementation of evidence-based programs and practices to make sure all people have the opportunity, knowledge and skills to fully benefit from their health care.

Third, I am here as member of the Institute of Medicine Committee on Psychosocial Services for Cancer Patients and their Families in a Community Setting. This is the group that authored the report that the Cancer Support Community and its member Gilda's Clubs have taken on as the backbone of their program for the future, under the leadership, I might add, of the Laura Jane Hyde, CEO, of Gilda's Club Chicago, who served as the chair of the Program Committee Task Force Committee for the Cancer Support Community.

I am here to honor and celebrate the Cancer Support Community and Gilda's Club institutional investment in realizing one of the most important ideas of our time: that psychosocial services for cancer patients are not merely a nice idea – they are necessary if we are to achieve -- as individuals and as a society -- the benefits of the advances in cancer diagnosis and treatment available today.

In taking on the challenge of implementing the recommendations of the Institute of Medicine Report "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs," the Cancer Support Community has taken a visionary step.

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Never before have we been able to make such a strong case for the importance of psychosocial services. Never has our advocacy been backed by such a conservative, mainstream and prestigious organization. And never has the need for psychosocial services by patients, health care professionals and health plans been so great.

I want to talk about why it is visionary that you have taken this on and demonstrate to you how the report provides you with both the justification and the occasion to act boldly to make a difference.

For about 25 years now, there has been a growing community of people who recognize in some way that cancer constitutes a highly disruptive series of events that people struggle – to a greater or lesser extent – to incorporate into their lives.

*Our illness and our ability to absorb the growing demands on us as patients undermine the potential effectiveness of our treatment.*

Many of us who recognize this are patients – some are researchers and some are clinicians. We are joined together by two common experiences: the first is our commitment to doing something about this, and second is the unfortunate experience of having our perspective marginalized by the medical community, which views it as largely irrelevant to their heroic efforts to treat and cure cancer. I won't dwell here on the reasons our conviction that psychosocial services are viewed as irrelevant. But I will say that it is time to move on. It's time to quit acquiescing to the prevailing views of busy oncologist and to re-frame the argument to match the demands of 21<sup>st</sup> Century cancer care.

Let me tell you a brief story to illustrate what I mean:

On my 20<sup>th</sup> birthday, I was diagnosed with an advanced case of Hodgkin Disease and spent considerable time on life support while my doctors tried to halt the cancer's galloping course through my body. I was devastated. I was just a child. I thought, "I can't die now – I'm just beginning!"

After I was well enough to go home, I began the daily trek to the hospital for weeks of radiation treatments, followed by two years of debilitating chemotherapy. I was skinny. I was hairless. And I was non-compliant.

Each time he administered my chemotherapy, my doctor would direct me to take six pills daily at regular intervals for the next two weeks. I didn't do it.

One day I might take two pills. Or six all at once. Some days I took none.

My doctor warned me to stay home because my immune system was at low ebb and I was at grave risk for infection.

I went out dancing.

I now look back at my behavior in awe: the millions of dollars worth of biomedical research that was distilled into the knowledge and experience and procedures and drugs aimed at a disease that was costing hundreds of thousands of dollars to treat ultimately largely relied on the actions of one weak, skinny, scared adolescent -- to have its impact. I had to show up. I had to cooperate. I had to take the drugs as scheduled. I had to avoid the risks.

I was not a very good patient. And I had no idea that the outcome of my care depended so heavily on my actions. The central role I had to play in order to achieve the potential benefit of the best available treatment has been brought home to me again and again – through two additional cancer diagnoses, the treatment of a dangerous heart condition and the ongoing management of the conditions and risks that result from that many diagnoses and that much treatment. I've learned the importance of taking on the complex responsibilities of a patient.

Even with my experience and expertise, I struggle to competently perform the many tasks that keep me upright and functioning. I am constantly impressed with the tools that are now available to treat cancer diagnoses that – even a decade ago – were death sentences.

And I am so very grateful for them.

But what is widely overlooked about these advances is the extent to which their success *depends on our participation*. *We* have to show up. *We* have to do the get the tests. *We* have to take the pills. *We* have to avoid the risks – or we don't realize the benefit. For example:

- Better surgical techniques mean we come home from the hospital quicker and sicker and have to manage the drug, dietary, wound-healing, and rehabilitation therapies that used to be delivered by professionals in the hospital.
- Better drugs now help many people live long and well with serious chronic diseases, but getting their full effect requires careful attention and sometimes a restructuring of lives around the demands of the medical regimens. And
- More specialists and tests and treatments mean that our administrative burden has grown as we coordinate appointments, information and insurance matters.

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**“What is widely overlooked about advances in the tools that are now available to treat cancer diagnosis is the extent to which their success *depends on our participation*. *We* have to show up.”**

Medical science has advanced far more quickly than have our expectations about our role in our own care. Too often we still don't realize our participation is not really a choice. It is not just a nice thing to do if we if we feel like it, we have a little extra time and good broadband access to look for new information. Our active, knowledgeable participation is necessary if our treatment is going to work.

I don't think most of us fully recognize this: almost no one has really thought through what it means to have a health care system that relies so heavily on us and our loved ones to realize its potential for improved outcomes.

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Certainly, there is no evidence that the oncology community realizes the extent to which their success depends on our cooperation.

Now as you know too well, there are many of us who will never be able to fulfill our end of the deal here: we are too sick already, we are alone, too young or too old, we are frail mentally,

our families don't have the resources or we lack the health literacy and the confidence to take on these highly complex tasks. But many more of us could do the work if we had a better job description – and effective on-the-job training and support as we move forward through our treatment and survivorship. To me, this is a description of psychosocial services.

Without the widespread availability and use of such services, we will squander the investment of our tax dollars in innovations in cancer care. We will waste the precious resources of the healthcare system. And we will not realize the improvements in survival that are possible, neither as individuals nor as a nation.

Conversely, psychosocial services are the tools through which we will, together with our oncologist, oncology nurses, radiologist, endocrinologists, social workers and rehab doctors, achieve the full promise of medical technology, surgery, procedures and drugs. Let me be specific here:

The IOM report identifies seven needs of patients in order to participate fully in their care and lists the types of services that have been developed to meet those needs.

For each service, the report provides either a systematic review of the available evidence to support its use or commentary about why such evidence is not required.

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All of us – and our loved ones need information about illness, treatments, and health services. While there is scant scientific evidence that information makes any difference in health outcomes, I defy anyone to design a study with an arm that withholds it. You at Gilda's Club know as do I that the only relevant information for any patient or caregiver is the right information at the right time.

Second: we sometimes need help coping with emotions to keep it together, to get out of bed, to care for our kids, adhere to our chemotherapy routine, or sometimes, do long-term follow-up. There is a strong evidence base that peer support groups, counseling and psychotherapy and the pharmaceutical management of

symptoms have an impact on mental symptoms such as depression on functioning, quality of life and adherence to medical regimens.

Third, managing the complicated tasks of illness is a real challenge for some of us – and as technology advances, this will only increase as we find ourselves coordinating complicated chemotherapy and dietary regimens and setting up our own IV lines at home. There is fairly solid evidence for self management but I believe we are going to need far more powerful interventions over time as the demands on our technical abilities grow.

Fourth, some of us need assistance to change behaviors to minimize the impact of disease. One need only think of the patient with esophageal cancer who is struggling to quit smoking to remember how our behavior can mute the effectiveness of medical interventions. Fortunately, there is solid evidence for the effectiveness of brief counseling and patient education.

Fifth, some of us need basic resources to take advantage of health care, from a babysitter during our radiation treatment, to getting a ride to and from chemotherapy such logistical barriers can make the difference between getting care or not. These solutions require no evidence.

Sixth, we need help managing the disruptions in work, school and family life. From coping with the threat of losing your job because of treatment to finding respite care for a husband with Alzheimer's during surgery -- the reality is that cancer *always* complicates lives that are already

complicated enough, and some people need emergency back-up to be able to fully participate in their treatment. Services like family caregiving support, home health help with activities of daily living and chores, and enforcing legal protections, such as the Family and Medical Leave Act, don't require scientific evidence to be critical to ensuring that all patients are able to engage in their care.

And finally, despite the recently passed health care reform bill, the crisis of the uninsured and the underinsured in our country will continue for the foreseeable future, and it goes without saying that many people need financial advice and assistance in order to for their cancer to be treated effectively.

I look at this list and I ask you to tell me "Exactly which of these services is not ABSOLUTELY CRITICAL to us engaging fully in our care? Which one of these services is just *nice*? Which ones are *optional*?"

Because I don't see any optional ones on this list.

The National Cancer Institute and American Cancer Society periodically wring their hands at the lag between the promises they have made about reducing cancer deaths and the reality on the ground. Well I can point to one of the main culprits: the hundreds of thousands of people in this country who, for lack of access to these services are unable to fully engage in – and thus benefit from – the treatments currently available.

Not one of these services on its own will drastically reduce the lag but by recognizing the central role of patients in the success of all cancer treatment – and by making available the full range of psychosocial

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services that reduce the barriers and support patients' successful engagement in their care, I'm betting that we could make significant progress.

The recommendations in this IOM report lay out the very practical, concrete steps that need to take place in order to reach this goal. The report makes 10 recommendations, but there is really only one you need to really understand in order to use this report to guide the work of Gilda's Club Chicago because this recommendation justifies your effort to address screening, referral, programs and continuity of care. That is the first recommendation, which describes what cancer care should look like. It is the one that says that in order to be considered of high quality, cancer care must include a number of key elements:

All cancer care should ensure the provision of appropriate psychosocial services. This means every oncologist, internist or primary care doc who is in charge of a patient's treatment must:

- Facilitate communication between patients and care providers
- Identify each patient's psychosocial health needs
- Design and implement a plan that
  - ✓ Links patient with services
  - ✓ Coordinates biomedical and psychosocial care
  - ✓ Engages and supports patients in managing their illness
- Systematically follow up on, re-evaluate and adjust the plan

So from our perspective, this is what care should look like:

- Every patient must be screened for distress – something that the new program of the Cancer Support Community and this Gilda's Club is taking on.
- Every patient's psychosocial needs should be assessed and referred appropriately. This is what's Gilda's Club *does*.
- Each person should have access to effective support and evidence based interventions.

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These services should be regarded as essential to the outcome of treatment as chemotherapy, rehab, radiation and surgery and should be coordinated seamlessly with them.

As many of you know, this is not the way care is delivered in the vast majority of practices, clinics and hospitals around the country. And making it become so is not the highest priority for busy health professionals who are completely absorbed in the technical and business aspects of delivering cancer care. The commitment of the Chicago Gilda's Club to focus on changing strategic parts of cancer care to conform to this standard represents a huge step toward getting there.

Well OK. Very nice. Really. What difference does this IOM report make? You could probably persuade me that these were all the things Gilda's Club has been doing for years, just not as clearly defined as they are here. Well here's the difference:

We have never before had all the evidence of the need for and the effectiveness of psychosocial services collected and presented in one place. At a time when evidence constitutes the gold standard that justifies changes in health care delivery, this is an extraordinary opportunity to align the Gilda's Club programs with the *needs* of patients and the *services* to meet those needs.

Another difference is the authority the Institute of Medicine imprimatur conveys. When you or I say "Every health care provider should..." those health care providers say "yeah, well, sure..." When the Institute of Medicine says it, this means that the recommendations carry the authority of institutionalized medicine. This legitimization may not be the winning lottery ticket, but at least we are in the game. This endorsement eliminates a number of critical barriers.

The IOM report makes a difference because regardless of how your Gilda's Club organized itself before, aligning your efforts with this very clear of standard means that you are placing value on things that relate directly to a set of measurable outcomes – that you have a strategic plan for what needs to be done.

By using this report as a blueprint for your efforts, you establish Gilda's Club Chicago as a national leader in the successful implementation of high quality cancer care that by definition includes the full range of psychosocial services. *Gilda's Club Chicago and the larger Cancer Support Community are necessary.*

And the final difference is that we never step into the same river twice. Just as our nation today looks different than it did last Monday, the challenges and demands of those clinicians providing cancer care are different today than they were even a couple years ago. They are only beginning to realize that their success depends on us as we patients are forced take on more responsibility for our own care.

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And because Gilda's Club Chicago will be right there with the evidence, the arguments, the resources, the skills and the knowledge, those clinicians will come to realize that only by incorporating this new standard of care will most of us patients be likely to do engage in our treatment.

Psychosocial services are one of the keys to their success. Treating cancer is no longer an elite enterprise of doctors wielding surgery, radiation and chemotherapy as their tools. Never before has it been so important for cancer treatment to become a shared project where doctors and patients, nurses and family members, counselors and social workers come together to work toward the shared goal of remission and cure.

By adopting the standard of care laid out in the IOM Report as your guide for the future, this Gilda's Club, as part of the larger Cancer Support Community is signaling that it's time to get serious. The services you provide to cancer patients are not ancillary or optional– you are now working directly to integrate the power of psychosocial services fully into cancer care – because this is what is required to help all of us with cancer live for as well as we can for as long as we can.

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**The Center for Advancing Health** conducts research, communicates findings and advocates for policies that support everyone's ability to benefit from advances in health science. Since it was founded in 1992, CFAH has aimed to increase the influence of evidence on health-related behavior and its determinants in the development of policies, practices and programs that draw this evidence to produce better health outcomes. For further information about the **Center for Advancing Health**, please call 202-387-2829 or visit [www.cfah.org](http://www.cfah.org).

**Gilda's Club Chicago** creates welcoming communities of free support for everyone living with cancer – men, women, teens, and children, along with their families and friends. Last year, the Club offered more than 250 activities each month and hosted more than 9,300 member visits. All programs are free. For more information about **Gilda's Club Chicago**, please call 312-464-9900 or visit [www.gildasclubchicago.org](http://www.gildasclubchicago.org).