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Awareness in Action

Meet Charlie Chemers, a Rolfe supporter who proves you're never too young to start giving back.



Northbrook, IL -- Last November, early morning visitors to downtown Northbrook were treated to a striking sight. Twelve-year-old Charlie Chemers, clad in a baseball cap and a purple **Rolfe Foundation DASH for Detection** t-shirt, was leading a group of 70 friends, neighbors, and family members on a charity walk to benefit early detection pancreatic cancer research. With Charlie at the helm, the party smiled, greeted pedestrians, and handed out lavender balloons.

The walk, dubbed *United in Purple*, was Charlie's mitzvah project – a charitable act invoking the Hebrew concept of tikkun olam ("fixing the world") that many young Jewish boys and girls undertake on their road to the Bema. He organized it in honor of his grandfather, Gary Schwartz, who had been battling pancreatic cancer since a diagnosis in January of 2015.

"Right away, as soon as Charlie became aware he'd have the opportunity to perform a mitzvah, he knew this would be his cause," recalled Charlie's mother, Dena, when discussing the walk recently. "We participated in the Rolfe Foundation's 2015 *DASH for Detection*, and Charlie was really struck by its purpose and spirit. When it came time for his mitzvah, he decided to emulate it, and to support Rolfe's work."

With his family behind him, Charlie got industrious. He designed a two-mile route for *United in Purple*, and proceeded to put the word out, sending email invitations to friends, family and classmates. He asked each participant for a modest donation of \$5 per person. Many gave much more.

When the walk concluded, Charlie presented an oversized check totaling \$2,155 to the Rolfe Foundation – a number that would balloon to \$2,800 as donations

continued following the event. Charlie posed for a picture in the local Northbrook newspaper as his mother and sister looked on proudly. And his grandfather, the guest of honor, beamed.

"There are some days in your life you'll never forget," observed Ms. Chemers recently. "It was such a special display of love, and of heart. My dad wasn't in great shape at the time, and we all sort of felt he might not be around much longer, but he was able to make it to the walk. And he was in great spirits. It was very special."

Sadly, only two days following the walk, Mr. Schwartz's health declined. He was admitted to the hospital on November 9th, and passed away eleven days later.

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Since the race, school and sports have occupied Charlie's time. He's a voracious reader who adores non-fiction; he plays center on his school's football squad; and he is a devoted fan of the Denver Broncos and Peyton Manning (his mother says he predicted Mr. Manning's Superbowl win at the start of the 2015 season). Yet wherever is attention may be focused, Charlie says his grandfather is never far from his thoughts.

At a recent visit to Mr. Schwartz's resting place, Ms. Chemers noticed her son carrying his grandfather's funeral pamphlet in his pocket. It had become a totem, Charlie explained. Something he always kept with him.

November 2016 may be a ways away, but Charlie is already planning a repeat walk. In fact, he

and his family want to establish it as an annual tradition. "November is pancreatic cancer awareness month," offers Ms. Chemers. "And we want to keep doing these walks not just to honor my dad, but to hopefully make an impact in the lives of other pancreatic cancer patients, and to further raise awareness of the disease itself."

If you're interested in supporting the Chemers family and their efforts, they encourage you to visit the [Rolfe Foundation's Community Events](#) page, where information about the walk will be shared as it becomes available.

Should you be able to participate, if you'd like to say hello to Charlie, and commend him on his good work – look for him towards the front of the group. He'll be the one taking point, leading the charge.



Committed to a Cure: Meet Maggie Brophy

When she was twenty-two, Maggie Brophy started the Rolfe Foundation's Young Professionals Board. Here's how she did it.

Chicago, IL || September 2016 -- As it stands today, the Rolfe Foundation Young Professionals Board is composed of more than 30 dedicated volunteers. Each member serves on an organizational committee, fulfills an annual set of financial goals, and contributes to a formidable calendar of fundraising events.

In 2015, the group raised just over \$70,000 in support of early detection pancreatic cancer research. This year, it expects to top \$100,000.

According to Maggie Brophy, the group's founder, the whole endeavor stemmed, "from a wild, wild whim." She chuckles a bit, then adds: "I'm only half kidding."

The whim occurred in late 2008 when Maggie was twenty-two, fresh out of college, and navigating the challenges of a new city, job, apartment, and life. With what little free

time she had, she was not, "thinking about organizing a team of volunteers to run an on-going series of large fundraisers."

But on a non-descript day in November, while working as an associate for a commercial real estate firm, Maggie happened to show an office space to Lynda Robbins, the Executive Director of a local, growing non-profit: the Rolfe Foundation. The unit, as Ms. Robbins notes, wasn't particularly striking. What was striking, however, was Maggie's immediate interest in the mission of the Foundation.

"My mother, Lorraine, was diagnosed with pancreatic cancer when I was a freshmen in high school," explains Maggie. "And she beat it! The tumor was found early, she had a successful Whipple procedure – at that time she had been cancer free for seven years. She was *the* statistic. It's a rare story, I know, but it really connected me with

Rolfe's mission – which is, in essence, to make stories like my family's the norm, instead of the exception."

Maggie volunteered to get involved with Rolfe then and there. "I explained there were a number of things she *could* do," remembers Ms. Robbins. "But I told her the thing the Foundation needed most was a pipeline to new members. We needed to start enlisting the next generation of impactful volunteers; which meant we needed a junior board." Maggie didn't hesitate.

"I said, 'I'll do it! Sign me up!'" she recalls, laughing at her gumption.

By her own admission, Maggie didn't know what she getting into. Building a membership, setting fundraising goals, organizing tax-deductible events – all of it was new territory. But she dug right in.

Maggie was the fiery engine behind the first three years of every YPB effort. She rallied friends and family (“I forced people to be involved”), wore every hat (“I was simultaneously President, Treasurer, and Secretary”), courted potential members (“basically anyone who showed even the slightest interest was invited to a meeting”), organized events (“lots of small meet-and-greets”), and eventually, her passion attracted other like-minded movers and shakers.

By 2011, Maggie had recruited a core membership who would help establish the group’s two annual signature events: *Cruisin’ for a Cure* and the *YPB Holiday Party*.

“What she did is amazing,” observes Robin Goldberg, a 2011 recruit and the longtime chair of *Cruisin’ for a Cure*. “Joining something like this and finding the time to even be a significant volunteer is one thing – but building it from scratch? It blows me away.”

During Maggie’s eight-year tenure with the Young Professionals Board, she has changed jobs twice, moved to and from Los Angeles, made significant strides in her career, found love, and got married. Very recently, she “graduated” from the confederation she founded, and joined the Rolfe Foundation’s governing *Board of Directors*, the first member of YPB to make that leap. “It’s well earned,” says Board President Kevin Braude.

Through it all, her parents couldn’t have been prouder. “They’re happy for me all the time,” Maggie muses, “but I know my mother has always been delighted by my work with Rolfe.”

Sadly, during the course of this writing, Lorraine’s health declined. She had endured a series of issues in the last several years, and died on August 16th, 2016. She went with her friends and family surrounding her, where they had been her life. Her loved ones took solace and in the fact that her death was not caused by cancer; she fought it twice, and won.

Following her mother’s passing, Maggie was given an opportunity to recuse herself from her current duties, co-chairing the 2016 ***YPB Holiday Party***. She declined to step aside, however, and instead doubled down her efforts. “My mother taught me you can’t stop fighting. She knew how lucky she was to overcome her initial diagnosis – but she never considered her life afterwards to be ‘extra’ time. I will always miss her, of course, but I’d rather celebrate her life than mourn her death. I think she’d want me to help give hope to others, and not stew in hopelessness myself.”

Maggie points out that thus far, YPB has raised approximately \$60,000 in 2016; which means to reach \$100,000 for the year, the *Holiday Party* needs to take in \$40,000. It’s a formidable goal, especially for a junior board. Yet to the surprise of no one who knows her, Maggie is undeterred.

If you want to support Maggie and join her at the event, you won’t need to go looking for her, she’ll find you. She will undoubtedly encourage you to volunteer, and join the *Young Professionals Board*.

Hopefully she will once again be successful.



Stephen and Lorraine Brophy

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rolfefoundation.org

Proactive Patients

Genetic Counselors at the University of Chicago are helping the families of pancreatic cancer patients be forward-thinking about health.



Chicago, IL || February 2017 - - According to University of Chicago genetic counselor Jessica Stoll, MS, CGC, the vast majority of patients who come to see her for a first visit have no idea what genetic counseling even is. "I think the word 'counselor' throws them off," she says, sympathetically.

For the most part, the people who are directed to Ms. Stoll and her colleagues at the University of Chicago's Gastrointestinal Cancer Risk and Prevention Team have been referred to the unit because one or more of their close family members has been diagnosed with some type of cancer.

"What frequently happens," explains Ms. Stoll, "is that when a patient is receiving cancer treatment, their family members receive crash course educations on numerous aspects of oncology. They learn about radiation, or chemo, or surgery – and sometimes they hear that a cause of a

particular cancer may be hereditary in nature. And that leads them to us."

Genetic counselors are employed in a variety of fields. Generally speaking, they work to identify and care for individuals who have increased risks of hereditary diseases or inherited disorders. As far as cancer care is concerned, genetic counselors consult with family members of cancer patients and help them determine whether or not the cancer in the family is related to an underlying genetic predisposition.

As a field, genetic counseling is relatively young, even within the still-developing world of DNA-related medicine and research.

The first program for genetic counselors was established at Sarah Lawrence College in 1969 through something of a fluke (the New York Times announced the creation of the

curriculum before it was officially green-lit; the ensuing public support for the discipline convinced Sarah Lawrence's leadership its conception had merit). The program, and the field itself, obtained a wider level of legitimacy and acceptance following the American Board of Genetics establishing an official certification exam for genetic counselors in 1981. Today, the National Society of Genetic Counselors has helped popularize the field among healthcare providers nationwide, and connects patients with appropriate local resources.

As far as the families of pancreatic cancer patients may be concerned, genetic counselors like those at the University of Chicago can play an instrumental role in a person taking ownership of their own health.

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"It's a very progressive school of medicine," offers Ms. Stoll. "We're playing detective, looking for something within a patient's DNA. Most medicine is reactive – you're treating an existing problem. When it comes to something like pancreatic cancer, we know it's hard to spot if you're not specifically out to find it; but since we also know it has hereditary properties - if we determine a risk exists, a patient can be proactive about their health management, and potentially address something earlier."

At the same time, Ms. Stoll notes, genetic counselors have to seriously consider a patient's mental health and wellness. "It's crucial that a patient understands what possible test results may mean, and what options will or won't be available if we discover something. For some people, having the information about risk is incredibly beneficial, for others, it's too much of a strain."

When a patient concerned about pancreatic cancer proceeds with testing, a counselor will undertake two investigations: first, they will create a familial map of cancer history through

medical records; then a patient may be offered a genetic test (usually by way of a simple blood test).

Counselors look for particular markers, testing approximately 20 specific genes. If no mutation is detected, on one level, the news seems reassuring. But as Ms. Stoll is quick to point out, because the hereditary causes of pancreatic cancer are not definitively known, a negative result "does not mean a patient has zero risk."

On the flipside, if a mutation *is* discovered, it doesn't necessarily mean a patient is guaranteed to eventually face pancreatic cancer – just that they have a higher risk of developing it. "No matter what, test results are complex," explains Ms. Stoll. "For some people, a positive test result is not necessarily heartening. But for others, the information is a positive, in that it may allow you to be forward-thinking."

If a patient has a genetic mutation, pancreatic cysts, or another potential precursor for the illness, their genetic counselor will consult with an oncologist, and typically schedule detailed annual

screenings - often alternating between magnetic resonance imaging (MRI) scans, and endoscopic guided ultrasounds (EUS). Some patients will never find anything and will never have to grapple with pancreatic cancer. For others, like Tom Collins, a physician in Maine, yearly screenings in a [Rolfe funded family registry at Johns Hopkins Medicine](#) allowed his physicians to diagnose his cancer in its earliest, most treatable stage. He credits the program with saving his life.

In 2016, the Rolfe Foundation hosted Ms. Stoll and her colleague at the University of Chicago, Sonia Kupfer, MD, for an [educational symposium](#) concerning genetic counseling. Since then, the Foundation's Executive Director, Lynda Robbins, has noticed an uptick of interest in the field.

"It's all part of raising awareness," Ms. Robbins says. "Cancer awareness is risk awareness. Just like how men and women of certain ages know it's wise to screen for breast and prostate cancer, we need to ensure people know that pancreatic cancer may be hereditary. If you know your risk, screening may help you manage it."