

2013 Report to Members of Seattle Children's Hospital Guild Association



Your Funding Focus investments are advancing lifesaving care and research for children and teens throughout the Pacific Northwest.

Read more to learn how...

Your impact is beyond measure

Your passion and commitment are making a difference at Seattle Children's. Because of your fundraising efforts, more children have access to groundbreaking treatments and expert care — regardless of their family's ability to pay.

Each year, a small portion of the funds that the Guild Association raises for Uncompensated Care is directed to priority research and clinical funding needs selected by the Guild Association Board of Trustees. Since this Funding Focus program was launched in 1994, the Guild Association has helped advance the work of many programs and facilities.

It's our pleasure to share with you updates about three of these programs, which have benefited tremendously from your contributions. Each year, we will continue to highlight the most exciting new discoveries and advancements that were made possible through your generosity.

If you have any questions about Funding Focus programs or this report, please contact Aileen Kelly, the Guild Association's Executive Director, at 206-987-4816 or aileen.kelly@seattlechildrens.org.

Funding Focus Programs — past and present

- Childhood Cancer Research (**current focus**)
- Autism Center (**current focus**)
- Adolescent and Young Adult Oncology
- Prematurity and Stillbirth Prevention
- Cardiac Innovation
- Integrative Brain Research
- Tissue and Cell Science Research
- Immunology Research
- Health Outcomes Research
- Infectious Disease Research
- Urology
- Janet Sinegal Patient Care Building
- Childhood Communication Center
- Brain Tumor Research
- Neurosurgery
- Intensive Care



Guild Association Board of Trustees

“It's exciting to see how our Funding Focus commitment is having an impact throughout Children's — really accelerating research and care that will improve children's lives.”

— Barbara Mann, Chair, Guild Association Board of Trustees



Thank you
for raising funds
that help so many
kids — like me!

Adolescent and Young Adult Oncology

For young adults with cancer, the term “care” entails so much more than the treatment of their physical body. Adolescents endure a particularly grueling psychosocial battle with cancer — often without access to typical support systems, like friends, school, sports and other peer networks.

So what do you do when you’re a young adult facing the biggest fight of your life, but you’re away from your home and your friends? You head to Seattle Children’s Adolescent Young Adult (AYA) Oncology Program, where other people are going through the same thing — and a team of experts is on hand to provide vital support.

The program was launched in 2007 to meet the needs of this specific and growing group of patients. Two years later, the Guild Association stepped in and made a \$1.5 million Funding Focus commitment that catapulted the team’s efforts forward. “That funding has been instrumental in helping our AYA Oncology Program become a national leader,” says Dr. Rebecca Johnson. With a full program in place, research studies underway and a new facility opening, Johnson says ours is a model for other centers. “Other hospitals that want to build AYA programs throughout North America are coming to see *us*, and it all ties back to the Guild Association.”

The Funding Focus dollars were used to underwrite important patient care initiatives, like the creation of novel fertility preservation videos for young men and women diagnosed with cancer. “Fertility is a huge issue for AYA cancer survivors. Because most teens and many young adults with cancer haven’t had all the children they want, it is crucial for them

to make rapid decisions about their future before starting cancer therapy,” says Johnson. Since no other videos like these exist, the AYA team went the extra mile and shared them via YouTube to create unlimited access for cancer patients beyond our care.

In order to further capitalize on YouTube’s relevance to young people everywhere, the AYA Oncology Program used Guild Association funding to produce an innovative video series called *Good Times and Bald Times*, which features teens discussing the issues they face during their fight against cancer. Other Guild-funded projects include education materials that are tailored to the needs of AYA patients, and a social media program through which young cancer survivors are encouraged to post.

Looking forward, the AYA oncology unit in Children’s new building will have even more to offer to young adults — like support groups that patients can log into by videoconference, a transition program for patients who are returning to home and school, and a neurocognitive rehab program that focuses on study skills and habits so patients can organize their complicated lives. In addition, having a dedicated wing will help patients gather to support each other and have fun — so a meeting room can easily be converted into space for an impromptu dance party.

Johnson sees the Guild Association as the lynchpin of the program’s success. “That funding has supported our efforts to carry the whole AYA oncology movement forward,” she says. “It’s been an incredible blessing to have this support.”

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— Dr. Rebecca Johnson, Medical Director, Adolescent Young Adult Oncology Program



Stronger with the Guild Association

What role did the Guild Association play in the famous *Stronger* video?

Funding Focus dollars for the Adolescent and Young Adult (AYA) Oncology Program were partly used to sustain the Artist in Residence program, which was initially established through a grant from **LIVESTRONG**. This program enables patients on the cancer unit to partner with visiting artist John Blalock — so they can express and cope with everything that’s happening in their lives. When John met up with Chris Rumble, a 22-year-old with leukemia, a very special idea was born.

Chris decided to make a video featuring his fellow patients and Kelly Clarkson’s hit song, *Stronger*, and Blalock brought together the video professionals to make the vision a reality. A media firestorm followed as the video became an overnight sensation. Clarkson herself was so honored that she recorded a video message for the patients in the cancer unit. Over 3 million people have viewed the YouTube video to date, turning it into an anthem for children and young adults with cancer around the world.

“Finding inner strength at a time when being strong seems like such an impossibility is what can pull you through cancer,” Chris says. “The kids in the video exude strength, and it was their courageous fight that made me stronger — that I will never forget.”

Dr. Rebecca Johnson, director of the AYA Oncology Program, is thrilled that the staff and patients were featured in this incredible message. “It can all be traced back to that funding for our Artist in Residence, and this is a great example of how the commitment from the Guild Association directly supported young adults on the cancer unit — and raised the national profile of our program, and Seattle Children’s, that much more.”

In the months since the video was created, Chris has completed his treatment and returned home. His leukemia is in remission, and he’s back to playing hockey and enjoying life in Wenatchee. “The most awesome moment was walking out of the hospital for the last time,” he says. “Done — never looking back.”

To see the *Stronger* video, go to:
<http://www.youtube.com/watch?v=ihGCj5mfCk8>



Chris Rumble takes time to make a young patient smile during his treatment at Seattle Children’s.

Immunity and Immunotherapy

For children with Severe Combined Immunodeficiency Disease (SCID), a lethal condition triggered by a defective gene, Dr. David Rawlings represents hope.

As the *Guild Association Endowed Chair in Pediatric Immunology Research*, Rawlings is an expert in the field and has developed a curative genetic therapy that could save the lives of children with SCID.

SCID is challenging because it hides out in a child's genetic code and becomes a catastrophic problem by the time it is diagnosed. The disease reveals itself through infections, like pneumonia and meningitis, typically in babies under a year old. These infections are very severe — and without extremely aggressive medical care, the child can die. That is an outcome Rawlings is working to change.

His vision is to establish a routine test that is administered to newborns. With a screening in place, children with the genetic defect that leads to SCID could be treated before the condition becomes life-threatening. "Once the defect is identified in a child, our diagnostic lab would quickly define which form of the disease they have and then our transplant group would meet to determine the best protocol and proceed to bone marrow transplant." By catching the disease before it results in infection, the likelihood of successfully treating it is much higher.

There are 25 types of SCID, and Rawlings' team is focusing on the most common one, called SCID-X1. He and his team have developed a type of virus, called a foamy virus, that can be inserted into bone marrow from a patient. The bone marrow is then returned to that same child, which results in a perfect donor match the immune system can readily accept. That cohesion creates a strong advantage for this type of therapy, and kids could be cured.

Rawlings' efforts have received significant attention, as well a \$12 million grant, from the National Institutes of Health (NIH). The grant will bring the idea forward to the point of a clinical trial — a true breakthrough in this field, which has never seen a clinical trial using foamy viruses.

Rawlings credits his Guild Association chair for much of his success. He uses his chair for salary support, so he doesn't have to charge his efforts to grants — and he can then maximize that funding to ensure his projects have critical staffing and supplies.

"I constantly leverage Guild Association funding to make additional work possible," Rawlings says. "Since the chair was established, we've made gene therapy breakthroughs, led the Northwest Genome Engineering Consortium and advanced type 1 diabetes research — all of it has been partially supported by the Guild Association."



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— Dr. David Rawlings, Guild Association Endowed Chair in Pediatric Immunology Research

Cardiac Innovation

Research has the power to transform the way patients are treated and cured, yet the road from the lab to the bedside can be very long and costly. At Seattle Children's Heart Center, the Guild Association is accelerating that process by supporting a groundbreaking new initiative that increases collaboration between scientists and clinicians — and ultimately brings the most promising treatments to patients as quickly as possible.

Four years ago, the Guild Association dedicated Funding Focus dollars to Cardiac Innovation — a bold effort to make our Heart Center one of the best in the nation. Dr. Mark Lewin, co-director of the Heart Center, says those funds have enabled his team to think about their work in a totally different way. “Our focus on the short term is more balanced with visions of how we'll change the future,” he says. “The funding is the seed that makes it possible to take risks on ideas that might be unproven but have very high potential to improve the lives of children.”

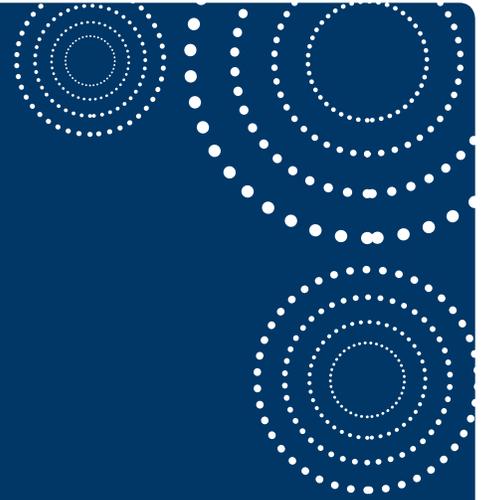
The most immediate project at hand is the Heart Center Research Initiative, a leadership team comprised of clinicians and scientists who are tasked with translating research advances into better patient treatments. Dr. David Reuter, who spoke at the 2011 Guild Association Annual Meeting, will co-direct the initiative — thanks in part to Funding

Focus dollars, which are helping make the position possible by supporting a portion of his salary. Reuter will partner with a co-director nationally-recognized in outcomes research whose recruitment is currently underway. Together they will create a small grants system to incubate new ideas, bring together teams of individuals who can fuel each other's projects and hire vital research support staff — again, all of which will be supported by the Guild Association Funding Focus commitment.

In turn, that initiative will make it possible to more rapidly bring research projects into the patient sphere, like a Guild Association-funded effort to use ultrasound technology as a therapeutic energy delivery tool that can create a passage in a blocked valve or seal tissues together without scarring. It will also spur the work of Dr. Mark Majesky and Investigator Lisa Maves to re-grow cardiac muscle in children with heart failure. Finally, it will turn Dr. Mike McMullan's research in artificial heart assist devices into practice, so patients can easily be matched with a unique pump type that will keep them alive until a heart becomes available for transplant.

These are the projects that represent the future of cardiac medicine — and hope for families of children with heart issues. Thank you for bringing that hope even closer through your Funding Focus commitment!





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HOSPITAL • RESEARCH • FOUNDATION

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