



## **RWRM UPDATE**

**October 2008**

So much has been accomplished by Ryan's foundation, RWRM, since our mailing of Spring 2008. This is our Fall 2008 update. We are successfully becoming a recognized part of a movement to improve cancer treatment for young adults. As you will see, we are allying and positioning ourselves where we can begin to effect real change, which is what we are all about.

Perhaps more than anything, we want to thank you for your continued support and generosity. Ryan would be proud of how many people are working to improve things for young people facing what he faced. Please know that every contribution you make is deeply appreciated and necessary to pursue his goals. As you will see below, we hope to direct the funds into training and fellowships that will change how young adults with leukemia are treated, forever. We are trying very hard to make a big impact, and we think we are succeeding. Read on!

We have included another copy of our Mission Statement to remind everyone exactly what it is that we are working towards. It inspires us every day. But, in addition, here are some facts:

*\*Every year, nearly 65,000 young adults in their 20s and 30s are diagnosed with cancer.*

*\*Cancer is the leading disease-killer among 20-39 year olds.*

*\*In contrast to younger and older cancer patients, survival rates for young adults have not increased since 1975.*

No one is certain of the reasons why survival rates are not improving for this age group, but some factors are a lack of insurance, less participation in clinical trials, and

delayed diagnoses. And in the world of blood cancers like leukemia, a major reason is that very often, the young adult is caught between the worlds of pediatric and adult oncology. This can result in the patient receiving treatment from caregivers who are not well-versed in the psychosocial and developmental issues facing young adults. This is the gap that Ryan wanted to bridge, and with your help we can make a significant impact.

### **1. Website: RWRM.org**

If you haven't recently clicked on our website (RWRM.org), please take another look. Todd Boerger is incorporating many improvements and is always willing to consider new ones. Let us know. If you didn't receive our Spring 2008 Mailing, you can find a complete copy there. We are making progress on many of the goals we listed, and will include updates on our progress as soon as we have firm news to report.

### **2. RWRM Wii Fishing Tournament**

Enclosed is a flyer inviting you to the **Ryan Waldheger Research Memorial Wii Fishing Tournament** which will take place beginning at 4:00 pm at Time Warp Bar in Westlake on the Saturday after Thanksgiving. Please try to attend. It will be an event to remember, and we really would like to have a big turn-out so that all of Ryan's friends and supporters can actually BE together. You don't have to compete in the fishing tournament itself, but we hope you will! Please e-mail us at [info@rwrn.org](mailto:info@rwrn.org) by Tuesday, November 24<sup>th</sup>, if you are interested in Wii fishing. The proceeds from this event will be used to donate several complete Wii systems, flat screen TVs, and mobile carts to University Hospitals transplant unit. Four Nintendo Wii Systems have already been generously donated by Dr. Tim Bizga, family friend and RWRM supporter. **November 29<sup>th</sup>, 2008**. Save the date and invite your friends!

### **3. Membership in the Lance Armstrong Foundation**

Any friend of Ryan knew of his admiration for Lance Armstrong. Ryan was one of the first to wear the yellow "LIVESTRONG" wristband. He made sure all of his doctors and nurses saw his and encouraged everyone to wear one. Largely due to his urging, they were worn by so many people at the Ireland Cancer Center that they became more common than not. Lance was Ryan's inspiration many, many times when things were rough.

This summer, RWRM was formally admitted as a member of the Lance Armstrong Foundation (LAF) and a member of the LIVE**STRONG** Young Adult Alliance (YAA). There are about 70 such member organizations, all with the goal to improve survival rates and quality of life for young adults with cancer between the ages of 15 and 40. We know how happy Ryan would be about this step. He believed that only by a strong national focus and fund-raising source would any change for the better be achieved. That is why he went to Washington on behalf of the Center for Regenerative Medicine. And that is why he would have been proud to have his foundation be one of the leadership groups spearheading Lance Armstrong's efforts.

#### **4. LAF Meeting in Austin regarding IRBs**

At the invitation and total expense of LAF (no cost to RWRM), we were invited to and attended a meeting (September 12-14) to design an educational package for the use of Institutional Review Boards (IRBs). IRBs are the bodies required to review clinical treatment protocols for use in any hospital. There are many hundreds of IRBs nationwide that review and help model the clinical trials approved and offered at their institutions.

Our meeting focused on how to educate IRBs about the special issues confronting Young Adults diagnosed with cancer to ensure that the protocols developed and used in Cancer Centers answered both the medical and social concerns of Young Adults. The goal is to immediately impact the process that hospitals follow in designing and offering cancer protocols for young adult patients. We want to alert IRBs to the issues that uniquely effect the 15 to 40 year old age group such as fertility, school requirements, scheduling of testing, recognizing support of boyfriends/girlfriends, siblings, and parents, special young adult-friendly approaches and facilities, etc. Often, these issues are not dealt with in either the current pediatric or adult protocols.

Ryan's case became a sort of model for the discussions and RWRM is currently a leading force in drafting the information for the IRBs. Our ultimate goal will be to amend the Federal Regulations that govern IRBs to recognize that FDA-approved protocols must include guidelines for facing the concerns of young adult patients. This week, we received word that the Lance Armstrong Foundation will indeed utilize RWRM-created content in educating IRBs, nationwide. We've enclosed the latest draft.

## 5. Presentation to LIVESTRONG Alliance Meeting in Austin, November 14 – 16

The LIVESTRONG Young Adult Alliance (YAA) invited us to participate in a national steering committee meeting November 14 – 16 (again, at their sole expense). In addition, we will be one of the two presenters to the entire conference before breakout sessions. The other presenter will be a representative of the Coalition of Cancer Cooperative Groups (<http://www.cancertrialshelp.org/>). This is a great opportunity for us to jointly present with a great organization.

Cancer Cooperative Groups are large groups of leading cancer hospitals that come together to do cutting edge studies and design treatment protocols. You may recall that Ryan was treated predominately on a clinical trial labeled “CCG 1882”. That means that it was designed and implemented by the Children’s Cancer Group, a large cooperative study group of major hospitals. Our partner in this presentation, CCCG, represents the coalition of all the cooperative study groups.

If you go to their website and click on “Trial Check”, you can, for free, search for the Clinical Trials available for your age and your diagnosis, and come up with a complete and updated list. This is a marvelous innovation that will answer the ongoing needs of young leukemia patients for accurate information, on the Web, to chart out their Plans A, B, and C. For Ryan, this meant “Hope”.

As a joint speaker, we will be presenting to the audience on young adult issues regarding enrolling in clinical trials, insurance issues, powers of attorney, and the informed consent process. **Young adults need these issues resolved for them so that they can wage the battle of their lives.** RWRM is going to help LAF solve these issues for all young adults.

## 6. RWRM’s Long Term Goal

Enclosed is a draft of a long term goal towards which we are actively working. In summary, RWRM believes that the actual treatment of young adults with cancer will not change dramatically until doctors with a specific focus on young adult cancer are trained and present in the major cancer centers, advocating the changes we are proposing and leading their departments. After all, it is the patient’s doctor that calls the shots, thank goodness. Many of us remember the heroic efforts of Dr. Kodish, Dr. Koc, Dr. Tse, Dr.

Gerson, Dr. Laughlin and others. But, these doctors need the support of doctors and departments specifically focused on the needs of young adults.

Our idea is to encourage year-long fellowships at major cancer institutions where those doctors already trained in oncology can spend a year specifically focused on the treatment of young adults. These fellowships would be jointly funded by local foundations, like RWRM, and sponsoring institutions, as well as a national organization like LAF. Once doctors have completed these fellowships, and met patients like Ryan, we are sure that they will be positive forces in changing the way young adults are treated at the hospitals in which they practice.

## **7. Partner in Rainbow Babies and Children's Hospital**

### **Department of Hematology/Oncology**

When Ryan was first fighting cancer, he knew that his greatest ally and friend was the Hematology/Oncology Team at Rainbow Babies and Children's Hospital. It is very fair to say that he loved these people. He wanted to help them in their mission in whatever way he could. Now, his foundation is officially a "Partner" with them. Please see our listing on their website and their kind words regarding Ryan's message (<http://www.uhhospitals.org/tabid/3174/Default.aspx>).

We are working with Rainbow's team to promote our long term goals with LAF and elsewhere. Not only is Rainbow a Top 5 U.S. Children's Hospital, but University Hospitals is currently constructing a dedicated Cancer Hospital (<http://www.uhhospitals.org/tabid/1347/Default.aspx>). Rainbow's leadership team has been very open to our ideas on making sure the new facility takes into account the needs of adolescent and young adult cancer patients. Ryan was featured in a video that promoted this new hospital. He would be so happy about our efforts and our impact on the project in his name.

We are working closely with the leadership of this Department to develop our ties within the Lance Armstrong Foundation, of which they are also a member. It is with their help that we hope to achieve our goal of Accreditation of Young Adult Blood Cancer Centers, and Fellowships to train doctors. It is our hope that Rainbow will be the *first* center so certified.

## **8. The Leukemia and Lymphoma Society Light the Night Walk**

On Saturday, September 27, 2008, a group of Ryan's family and friends walked in honor of Ryan at Progressive Field for Cleveland's Light the Night Walk. Team Waldheger was led for the second year by team captain Jeff Suchy. Many thanks go out to Jeff for organizing the team. We also would like to thank the many that walked and donated to this wonderful cause and in honor of Ryan. Team Waldheger raised \$4,387 for The Leukemia and Lymphoma Society! We plan on making this an annual event so please contact Jeff Suchy or Becca Waldheger if you are interested in walking next year.

## **9. Lesjak Planning Corporation Charity Golf Classic**

RWRM wishes to thank the Lesjak Planning Corporation for dedicating the proceeds from their 5<sup>th</sup> Annual Golf Outing to the Ryan Waldheger Research Memorial. Held on September 15<sup>th</sup>, 2008, the event raised \$5,000, a sum that was publicly presented to RWRM director Michael P. Coyne at the event's closing presentation. Donations like this are quite remarkable, and we are honored by the generosity of our friends at the Lesjak Planning Corporation.

## **10. Team In Training / Athletic Events in Ryan's Honor**

Beckie (Lesjak) Walton of Cleveland, Ohio will participate in The Leukemia and Lymphoma Society Team In Training's P.F. Chang Rock 'n' Roll Arizona Marathon (Phoenix - Tempe). Beckie is inspired by Ryan's story and hopes to raise \$3,800 in Ryan's honor for the Society.

Mindy Rickert participated in The Leukemia and Lymphoma Society's Nautica New York City Triathlon in Ryan's memory. Mindy raised \$2,700 with some matching donations still coming in.

Steve Dzurec contributed the proceeds of his annual "Richfield Invitational" volleyball tournament to RWRM. He also donated funds raised by his Lakewood (OH) rec basketball team's guest bartending night (Around the Corner Tavern, sponsor), for a total of \$669. Go Steve and players!

## **11. 2008 Wine Tasting Open House**

On May 29<sup>th</sup>, 2008, Christy and Paul Stark, Nancy and Mike Rodeno, and Kathy and Dave Huffman hosted a Wine Tasting Open House to benefit RWRM. Wine donations were provided by Wine Shop at Home Independent Wine Consultant Robin Moodley, Theresa Sandhu, and the hosts. Donations, including anticipated matched gifts from several companies, total \$6,425! Thanks to all parties involved – the turnout was wonderful and the event unforgettable.

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We could continue this update and tell you about many more ideas, contributions, well-wishes, and status reports from inside RWRM and from all of its friends and supporters. Indeed, we are sure we are failing to recognize and properly thank some people who are our biggest supporters and who carry Ryan's message much further than we ever could alone. We hope you will accept what we know Ryan would say to all of you, very simply, and from the heart:

"Thank you, and let's keep it going."

He said that every day, and we remember it every day. We are working hard to make a real and lasting impact on cancer care for young adults. And, as friends of Ryan know, you can't set out to do anything in Ryan's name without giving it your best, and a little bit more.

The Ryan Waldheger Research Memorial

Board of Directors