

Join #46 Ryan Dempster in helping

Strike Out 22q

Dempster

Family Foundation

★ 46 ★



\$2 MILLION | 2 YEARS



STRIKE OUT 22Q!

★ RYAN AND JENNY DEMPSTER FAMILY FOUNDATION ★

Ryan Dempster photo courtesy Chicago Cubs/Stephen Green



ABOUT THE FOUNDATION

The Ryan and Jenny Dempster Family Foundation

The Ryan and Jenny Dempster Family Foundation is dedicated to raising awareness of 22q11.2 deletion (DiGeorge Syndrome/Velo-cardiofacial syndrome or VCFS) and families of children with this disorder – and the charities that support them – helping them deal with the challenges they face every day.

The Dempster Foundation lends support to charities and other organizations helping children with 22q11.2 deletion (DiGeorge Syndrome/VCFS) through monetary grants, educational and fundraising programs and increased community awareness.

The Dempster Foundation empowers organizations to help children with rare illnesses overcome difficult situations through:

- ★ providing funding to continue research for early detection of this disorder in children,
- ★ supporting programs about 22q that provide education, physical therapy and activity to promote long term well being,
- ★ creating initiatives that build and instill confidence in these children,
- ★ developing a 22q network for families affected by this disorder to share stories and help navigate healthcare options and treatment.

OUR STORY

Riley Elizabeth Dempster

Ryan and Jenny Dempster's beautiful daughter Riley was born in April 2009 with 22q11.2 deletion (DiGeorge Syndrome/VCFS), a disorder caused a deletion on the 22q11.2 chromosome, that seriously impeded her ability to feed and swallow. At only one month old, Riley settled into Children's Memorial Hospital for 12 long weeks of testing; physical, occupational and speech therapy; surgery to insert a trach and a g-tube for feeding; and a procedure called a Nissen Fundoplication to reduce reflux into Riley's esophagus. One tough little fighter,

Riley finally went home to round-the-clock care (and some fun too, even attending a few Cubs games). Now, 1-year-old Riley is doing great. She's still on a trach and feeding tube, but she is hitting developmental milestones right on target. She is even cooing and trying to speak when the passy-muir valve is attached to her trach. Riley and her family have a long way to go, as do all the children with 22q deletion and their families. But thanks to her early diagnosis, extraordinary care and the Dempster's ongoing commitment, she is well on her way!

Photo courtesy Will Byington



Photo courtesy Will Byington



THE DELETION AND ITS MANY NAMES*

The Chromosome 22q11.2 Deletion Syndrome goes by many names most often including DiGeorge Syndrome (DGS), velocardiofacial syndrome (VCFS), and conotruncal anomaly face syndrome (CTAF). In addition, there are patients with the deletion who were previously diagnosed with Opitz G/BBB syndrome or Cayler Cardiofacial syndrome. There is no detectable genetic difference amongst these patients as they all share the same underlying cause of their variable medical issues – a deletion on chromosome 22q11.2.

The Ryan and Jenny Dempster Foundation is striving to educate and unify both the public and professionals in their fight against this difficult disorder.

The Syndrome

A syndrome is a collection of findings, often seen as a recognizable pattern of physical and behavioral features that are consistent from one individual to another. The 22q11.2 deletion syndrome is caused by a very small missing piece (microdeletion) of chromosome 22 which is present from the time a child is conceived and is generally found in every cell of the body. Present in 1 out of every 4,000 live births at minimum, in 1 in 68 children born with a heart defect, and in 5 to 8 percent of children born with cleft palate, the 22q11.2 deletion is almost as common as Down syndrome, a widely recognized chromosomal disorder. The deletion has the potential to affect almost every system in the body and can cause a wide range of health problems. No two people are ever exactly alike, even when they have the same syndrome, and not every person with the deletion is affected in the same way. Though not always present, the key characteristics of this diagnosis include combinations and varying degrees of:

- Congenital heart defects
- Feeding, swallowing and other gastrointestinal problems
- Immune issues leading to difficulties in fighting infection and autoimmune problems
- Cleft palate, cleft lip and palate, hypernasal speech
- Kidney differences
- Hearing loss
- Low calcium and other endocrine issues such as short stature
- Developmental and speech delay
- Behavioral, emotional, and psychiatric differences (ADHD, autism, anxiety, etc.)

Diagnosis and Next Steps – Resources to Support 22q Families

Most children and adults with the 22q11.2 deletion can live productive lives but often this requires extensive medical care and emotional support for both the individual with the deletion and their families. All too familiar with these needs, the Ryan and Jenny Dempster Foundation offer these families the opportunity to meet other children and adults with the 22q11.2 deletion and converse with them over diagnosis-specific internet sites. Family meetings and picnics, support networks, and camps specifically designed for children with the 22q11.2 deletion are but a few of the resources that help families realize one of the most important truths in facing life's most difficult challenges – they are not alone. Please visit our website, www.dempsterfoundation.org, to learn how to access these and other resources for dealing with the 22q11.2 deletion (DiGeorge Syndrome/VCFS) and related disorders.

* Reprinted with permission from Donna M. McDonald-McGinn, MS, CGC, The "22q and You" Center, The Children's Hospital of Philadelphia.

FOUNDATION PROGRAMS & PROJECTS

Riley's Team

Riley's Team was created to encourage people to "join us" in the fight to raise funds and awareness about DiGeorge Syndrome/VCFS. Funds raised in this campaign will directly support testing for newborn children to screen for genetic disorders like 22q11.2 deletion (DiGeorge Syndrome/VCFS). There are different levels of donation; all donors receive their name listed as a MVP on the Foundation Wall of Fame on our website, as well as Foundation quarterly updates.

Riley's Road to CHOP (*Children's Hospital of Philadelphia's 22q Clinic*)

Through a partnership with the Ronald McDonald House and various airlines, the Dempster Foundation offers grants for three families each year to travel to Children's Hospital of Philadelphia (CHOP) to go through the 22q11.2 deletion consultation experience in the 22q Clinic. The Foundation works directly with CHOP to identify and address the needs of families unable to finance the expense on their own.

Riley's Place – *Dempster Foundation's 22q Clinics*

The Dempster Foundation is targeting specific cities to create 22q Clinics within select hospitals. These 22q Clinics will specialize in dealing with children with a 22q11.2 deletion and the broad array of issues that can be associated with the disorder. With a focus on the collaborative healthcare model, these 22q Clinics will continue to have physicians within multiple specialties working together to ease the burden and close communication gaps. The first clinic is scheduled to open in early 2011.

Power 2 the Parents – *Parent Empowerment Program*

The Dempster Foundation's Power 2 the Parents is an educational program that supports families of children with a 22q11.2 deletion, providing them with user-friendly templates for communicating information, and compelling dialogue to help them drive awareness of the disorder within their own communities. The educational program suggests ways for parents to handle communications with doctors and educators, and provides an outline to maintain constant and consistent communications with the child's healthcare/education providers.

Dempster Foundation 22q Conferences Sponsorship

The Dempster Foundation's 22q Conference Sponsorship program supports the medical community and conference planners to provide a wider geographical offering of conferences and parent meetings specific to the 22q11.2 deletion for families and healthcare providers.

COMMUNITY INITIATIVES

TEAM DEMPSTER

The Foundation is grateful to the many corporate partners and individuals that have joined us in the fight and made it their mission to help raise awareness and funds for 22q11.2 deletion. We are looking for more team members to help us reach our goal of \$2 million in 2 years. Two ongoing TEAM DEMPSTER programs include:

Strike Out 22q Days at D'Agostino's Pizza and Pub

Join the team to *Strike Out 22q!* For every pizza purchased on the 22nd of each month at D'Agostino's Pizza and Pub, \$1 will be donated to the Ryan and Jenny Dempster Family Foundation to help support families of children with 22q11.2 deletion. Place your orders today at any one of the four D'Agostino's locations in Chicagoland or visit www.dagsdelivers.com.

Candyality's Cubbie Gummies Program to support 22q

Candyality, a local Chicago candy store derived from the concept of associating candy with people's personality profile, has partnered with the Ryan and Jenny Dempster Family Foundation to raise funds to support children with a 22q11.2 deletion. Candyality will donate \$1 per pound sold of their #1 selling Cubbie Gummie Bears to the Foundation throughout the 2010 Cubs Season. For more information or to order online, please visit www.dempsterfoundation.org or www.candyality.com.

The Ted Lilly Strikeout Challenge

For every strikeout in the 2010 season, Chicago Cubs teammate Ted Lilly will donate \$10 to *Strike Out 22q*. He will also donate \$1,000 for each win he posts this season. Join in on Ted's Challenge at www.dempsterfoundation.org.

Other Community Outreach

Ryan participates in other community initiatives through the Chicago Cubs including the Dempster Dugout Program, the RBI Program and the Military Families at Wrigley programs. **Please see our Foundation website for more details (www.dempsterfoundation.org).**

Please see back cover for a partial list of 22q11.2 deletion resources.



★ WAYS TO GIVE ★ JOIN THE TEAM ★

JOIN THE TEAM of sponsors and friends helping to raise **\$2 Million in 2 Years to Strike Out 22q!**

MAKE A DONATION TODAY!

Make a tax deductible donation through PayPal on our website at www.dempsterfoundation.org, or you can mail a donation to the address below.

The Ryan and Jenny Dempster Family Foundation
P.O. Box 371
Lawrenceville, GA 30046

Thank you in advance for your support in helping us raise funds for children with 22q11.2 deletion (DiGeorge Syndrome/VCFs) in need.

TEAM DEMPSTER

TEAM DEMPSTER is group of businesses and Foundation friends that have made the commitment to help support the Ryan and Jenny Dempster Family Foundation! Whether it's through a personal fundraiser, a retail opportunity or everyday donations, we are grateful to those who have made it their mission to find fun, creative ways to help us raise funds for 22q11.2 deletion research and support for families.

For more information on how to begin your own TEAM DEMPSTER fundraiser, please contact Terri Grunduski at 312-415-9846.

Thank you to the following TEAM DEMPSTER businesses and individuals: D'Agostino's Pizza and Pub, Candyality, State St. Barbers, Bernie's in Chicagoland,

Dog-a-holics Dog Boutique, Mike Lavorato, Derrek Lee, Ted Lilly, Rich Melman and Paul Powers. Please visit the Foundation website for a complete list of team members!

FOUNDATION FUNDRAISERS

New fundraisers are announced regularly on the website – so please check the website for the current opportunities to help us reach our goal of raising \$2 million in 2 years for the Foundation!

The first annual Dempster Foundation fundraiser will take place this summer; please visit our website at www.dempsterfoundation.org for more details. Come join us for food, mingling, great auction items and a special night of giving back.

HOW TO RECEIVE HELP

Grant Information

The Ryan and Jenny Dempster Family Foundation has an annual grant cycle, which closes in early November. Priority will be given to organizations located in the following areas:

- Illinois
- Arizona
- British Columbia, Canada

Grant Applications are available on line at www.dempsterfoundation.org; Grant Recipients are announced in late November.

22Q11.2 DELETION RESOURCES

Below please find a partial list of resources for families living with children with 22q11.2 deletion (please see the growing list on our website's home page for more options):

The International 22q11.2 Deletion Syndrome Foundation (www.22q.org)

Velo-Cardio-Facial Syndrome Educational Foundation, Inc. (www.vcfs.org)

Information on DiGeorge Syndrome (ImmuneDisease.com)

Children's Hospital of Philadelphia's 22q and You Center
(www.chop.edu/service/22q-and-you-center/home.html)

Chromosome 22 Central (www.c22c.org)

American Heart Association (www.americanheart.org/presenter.jhtml?identifier=3018193)

Max Appeal (UK) (www.maxappeal.org.uk)

Mayo Clinic (www.mayoclinic.com/health/digeorge-syndrome/DS00998)

CONTACT US

Thank you for your interest in the Foundation! For more information on sponsorship opportunities, ways to give back through in kind or monetary donations or to volunteer, please contact us at the following:

The Ryan and Jenny Dempster Family Foundation

P.O. Box 371
Lawrenceville, GA 30046
(404) 308-9300 Atlanta
(312) 415-9846 Chicago

Or please send us an email to: info@dempsterfoundation.org
Website: www.dempsterfoundation.org

OUR PARTNERS



A special *Thank You* to our Foundation sponsors to date; we could not do this without you!



Foundation Heavy Hitters