



**Bennett
Clayton
FOUNDATION**

B C F

For Children with OI

news

from Bennett and his family

volume 1 issue 1

4th Annual Charity Golf Event



Bennett teeing up the first drive of the 2006 golf event.

Mark your calendars! BCF's annual golf event will take place on Friday, August 10, 2007 at Shoreland Country Club. Watch for registration materials in your mail or contact us. It promises to be another great day of golf, games, prizes, good food, great company and most of all—a worthy cause. The Foundation sincerely appreciates the generous support of past golfers and sponsors, as well as friends and community members who donated prizes and attended the dinner. We always have room for more golfers. If you like to play golf and you like to have fun with other great people, don't miss it! Non-golfers are always welcome. ■

First Edition

We are grateful to all of you who have been part of the success thus far of the Bennett Clayton Foundation for Children with OI. In this very first newsletter we will bring you up to date on the Foundation's activities and connections to other friends and organizations. There is much more to share and we look forward to future issues where we will focus on sponsors, on OI, on Bennett and everyone impacted by OI. Please tell us what you think and what you would like to read in the next issue! ■

Wells Fargo Golfs for BCF

In 2005 and 2006 Wells Fargo Bank's corporate office selected the Bennett Clayton Foundation for Children with OI as the recipient of proceeds from their annual charity golf events. Coordinated by Patty Chouanard-McAdam, Wells Fargo employees, vendors, associates and sponsors enjoyed a day of golf at Wild Marsh and Stonebrooke Golf Clubs. These events generated nearly \$40,000 for BCF. We are humbled and overwhelmed by their generosity. Thank you Patty, for your efforts on our behalf. ■

The mission of the Bennett Clayton Foundation for Children with OI is to raise funds for education, research and support for issues affecting children with Osteogenesis Imperfecta. Funds raised will not go directly to Bennett or his family.

Our Sponsors



In the Beginning...

When the DeBlieck and Olson families first learned Bennett had OI, we quickly decided we had much to learn, much to do and that there were many more people who needed our help. The first golf event was born and we went to work. But we didn't do it alone. Many people stepped forward as sponsors. In this column, we will acquaint you with some of them. In future issues of this newsletter, we will acknowledge many others.

That first year, five companies or individuals became our "Birdie Sponsors". Four of those were local friends and business associates who recognized the merit in our efforts and very generously gave of themselves. Davisco Foods International, Pell Insurance & Real Estate, Ryan Plumbing & Heating are companies owned by local families. Wausau Supply Company's area representative, Dave Ebeling, lives here. The remaining sponsor was the Garber Family, friends of Bennett's family.

We will always be grateful to those five sponsors who helped us...in the beginning. ■

Personal Health Grant Deadline

The semi-annual deadline for **The Bennett Clayton Foundation Personal Health Grant** is quickly approaching. Deadlines of June 30th and December 31st have been established for this grant. Based on the following guidelines, BCF invites applications which will be considered after the June 30, 2007 deadline. Applicants may request up to \$2,500.00. Please see our website for more information and an application form—www.bcfforoi.org.

The BCF Personal Health Grant will be issued to patients who have been diagnosed with Osteogenesis Imperfecta in accordance with the following guidelines:

- be a resident of Minnesota
- be 17 years old or younger
- have a physician's diagnosis of Osteogenesis Imperfecta (OI)
- show financial need
- funds to be used for one or more of the following:
 - orthotics/braces
 - physical/occupational therapy
 - dental intervention (due to OI)
 - wheelchair/walker/crutches (or other mobility aides)
 - hearing aids (due to OI). ■

Personal Health Grant Awarded

The first BCF Personal Health Grant was awarded in 2006 to a Minnesota child in need of special dental care as a result of her OI. Awards will be reviewed twice each year. See article above for requirements and application materials. ■

Wine & Art

Invited guests attended *On the Town: An Evening of Wine & Art* on April 14th in the Governor's Room of the St. Peter Community Center. Along with a major sponsorship by MGM Liquor Warehouse, supporters provided monetary sponsorships and artwork for auction. Music by Rebecca Richards and delicious hors d'oeuvres entertained attendees as they bid on auction items and sampled wine from several vendors ■



Chad DeBleck and Karl Olson enjoying the festivities at our second very successful Wine & Art event.

News from OIF

Thanks to the Bennett Clayton Foundation, research into treatments and a cure for osteogenesis imperfecta (OI) is moving rapidly. Recent discoveries are extremely promising. A new recessive form of OI was discovered this year, bringing new understanding about how OI is inherited in families.

A major breakthrough in the search for a cure resulted in a new method to target and repair the faulty OI gene. This research is in large animal trials right now. This cure could be available for human trials in the next 5-10 years.

We are also studying new drug therapies that may increase bone density and strengthen the bones so that there are fewer breaks and deformities.

In April 2007, 60 of our nation's best OI researchers met to share their expertise and collaborate on a historic document that defines standards of care for treating people with OI. This will put an end to "best guess care", and begin a new era of evidence based quality medical care for people with OI of all ages. In concert with this, the Osteogenesis Imperfecta Foundation is developing Linked Clinical Research Centers to increase opportunities to improve care and speed up research progress. ■

Heller An Shapiro, Executive Director, Osteogenesis Imperfecta Foundation



Heller An Shapiro,
Executive Director, OI Foundation

National Conference of the OI Foundation

Nine members of the DeBleck and Olson families traveled to Omaha in July, 2006 for the biennial conference of the OI Foundation. There we experienced and learned more than we ever expected! We attended seminars and presentations on research, medical technologies, and therapies. The conference afforded us the opportunity to meet others experiencing Osteogenesis Imperfecta in their lives and to interact with professionals working with OI. Along with many other generous donors, BCF was recognized for its contributions to research funded by OIF. The next OIF Conference will be held in Washington, DC in 2008.

For more information on the OI Foundation, please visit www.oif.org. ■

Local Grants

Support has been provided to the BCF for Children with OI by **Benco Electric Cooperative** and the **Carl & Verna Schmidt Foundation**.

Benco Electric offers its customers the opportunity to "Round-up" their payment to the next dollar. That extra revenue goes into a fund which is awarded to non-profit applicants. This award to BCF will be used in support of local projects and personal health grants.

The Schmidt Foundation is funding the production of this newsletter and informational brochures. An earlier grant from the Schmidt Foundation helped to fund initial costs to establish BCF as well as our support of research into the cause and cure of Osteogenesis Imperfecta.

Support and confidence shown by these local organizations is sincerely appreciated. ■



Left to right: Bennett, Marianna, Kaitlyn and Lauren aboard the BCF float in the St. Peter Winterfest parade.

Part of the Community

On a cold winter night in February (above), friends of the Bennett Clayton Foundation participated in St. Peter's Winterfest 2007 parade. While walking and riding a float, we passed out candy, treats and information about our foundation.

Meet & Greet

On February 10, 2007 the Bennett Clayton Foundation hosted a gathering of families affected by OI. At the St. Peter Community Center, children and adults made new friends, renewed acquaintances, enjoyed refreshments, played games, made crafts, and formed the beginning of a network for OI in Minnesota. We hope to gather again this year. Our thanks to the Confirmation Class of Union Presbyterian Church and their advisor, Craig Drager, for assisting with games, crafts and child care. ■



Bennett...

- ...celebrated his 5th birthday on January 24th
- ...caught his first fish for the season on Lake Washington on May 1st
- ...graduated from St. Peter School Readiness - Discovery Days 1 on May 14th

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