Taco John’s Raises Record Amount for CFA

TACO JOHN’S
The Fresh Taste of West-Mex

CFA has been privileged to have enjoyed the friendship and generosity of Taco John’s stores since at least 1998. Each year, Mike Sartwell, who is himself a Taco John’s franchisee, takes it upon himself to organize and spearhead the project to help young people with cystic fibrosis.

It started with a Nachos Navidad promotion, which donates a portion of each of that product sold leading up to the Christmas Season. Then it grew to include an opportunity for customers to buy a Whiplash ornament (remember the rough-riding monkey in the Taco John’s commercials), and now offers a variety of ornaments for purchase during the season, the proceeds of which are included in Taco John’s donation to CFA. It also includes donation boxes located in some of the Taco John’s stores.

This year, Taco John’s surprised CFA with a check for $19,171. That amount represents the largest amount we have received in any year from Taco John’s. To place this into perspective, throughout the history of our relationship with Mike Sartwell and Taco John’s stores, CFA has been the beneficiary of more than $163,000 in generosity through the cooperation of area Taco John’s franchisees.

Please help us to thank Taco John’s for their cooperation by stopping into one of their stores to say “thanks” and while you’re there, you may as well have lunch. We realize it takes extra time and effort for them to help us during a busy season, and we want them to know just how much their support for kids with cystic fibrosis is appreciated by us all. Thank you, Mike, and the Taco John’s family!

Giving Hearts Day 2013 is a Success for CFA

On February 14, 2013, Dakota Medical Foundation (DMF) and Impact Foundation held the 6th Annual Giving Hearts Day. For one day only, DMF and other community donors agreed to match online donations of $10 or more made through impactgiveback.org to charitable causes of which the Cystic Fibrosis Association was one. All the participating nonprofits received in-depth fundraising training from the Impact Institute. Giving Hearts Day gave them an opportunity to build their capacity for online fundraising.

Being the first year in the program, CFA set what we thought was a realistic goal of raising $2,500 in the 24-hour period during which the giving occurred. As a result of the generosity of many who read this newsletter, we raised almost 250% of that amount.

We sincerely appreciate the enthusiasm with which you responded. We are looking forward to next year’s Giving Hearts Day when we hope to again participate in this tremendous program.
CFA Family Changes

Maybe part of it is due to me getting older. Maybe part of it is because so many things are changing in the world each day and it is natural to appreciate and prize what and with whom we have been associated. Or maybe it’s just because the work we do and the cause we pursue is so valuable to us, and the work we do together is important to us. As such, when changes happen and one of the team chooses to leave after 11 years, it is not without a degree of sadness.

Nancy Pandolfo has decided that it is time for a change in her life, and as such, ended her time as a CFA employee at the end of March 2013. For those of you who have met and worked with Nancy, you have an idea of the contribution she has made to CFA. Those of us who worked with her and relied on her steady hand at the wheel of many of CFA’s fundraising ventures, will miss her as well.

However, Nancy believed it was the right time and the right thing for her to do. In her typical manner, Nancy offered to help with the transition to another Development Director in any way possible and even indicated she would be volunteering at some of the events in the future. As much as we appreciate all the volunteer help we receive, that help may be appreciated even more.

The great news is that CFA has found someone who will carry on the duties and activities that contribute so much to funding CFA programs and services.

Pam Thompson is a wife and mother of six children who lives in Bismarck with her husband, Matt. She has experience volunteering and coordinating volunteer activities. She enjoys coordinating projects and has a heart for those who need help. And she is quite familiar with social media and website editing, which lowered my blood pressure immediately.

CFA appreciates the manner with which you as volunteers worked with Nancy to help CFA achieve its goals in the past. We encourage you to take your first opportunity to come and meet Pam while we continue to work toward our goals of fighting cystic fibrosis.

Thank you, Nancy! Welcome, Pam!

Donations Directed Towards Ongoing Need

Our thanks are again extended to area friends for the ongoing giving taking place that help us to provide the programs serving our young members with cystic fibrosis. Some persons with cystic fibrosis reach a point in their lives when their lungs have deteriorated to a degree where the most viable option is a double-lung transplant. CFA is presently funding multiple matching lung funds for members in that situation. CFA receives thanks from members for these programs, and it is our turn to pass along that appreciation. Donations to CFA help us to provide this service to our members.

Through the actions of Anne Helbling, the Aetna Giving Campaign donated another $100 to CFA. The Hague, ND Knights of Columbus St. Mary’s Council #5298 also donated $100 to the programs CFA provides for area young people with cystic fibrosis.

Some who responded to our Holiday Giving appeal included Michael & Sharon Heppner who donated $200, James & Sandra Nelson who donated $100 and the Fargo Amvets Post #7 also donated $100. Bismarck’s Robert Miller Elementary School donated $166 through its “Month of Caring” activities. The City of Minot Employees donated $400 again this year to help CFA fund its program services.

Kristi Hollar used the Volunteer Match offered by Daiichi Sankyo, Inc. to have the company donate $1,000 as a match for the volunteer work she did helping CFA. The Duska LaCount Charitable Annuity donated another $2,500 to CFA so that programs such as the lung fund match can exist to help persons with cystic fibrosis.

As mentioned elsewhere in this newsletter, donors contributed approximately $6,150 to CFA during Giving Hearts Day. Notable contributions to CFA on that day were: Sue Kramer—$1,000, Richard & Lynn Hentges—$250, Shelly Goroski—$200, Connie Sundby, Pam Wohlwend, Dan & Phyllis Lien, Dean & Ardella Deis, Todd Porter, Bob & Tamie Aberle, Jay & Jean Beyer, Tina Bichler, Richard & Sharmae Vetter, Jeff & Sherrie Skuza, and Chris & Nicole Hahn each donated $100.

Applying elsewhere in this newsletter, we again acknowledge the contribution by area Taco John’s franchisees of $19,171 to help CFA carry out its job of helping area individuals and families fighting cystic fibrosis.

We appreciate these gifts made to assist families in their day-to-day fight against an unrelenting disease. Without your help, we could not help.

Foundations, service clubs, corporations, cooperatives, local businesses, public employees, schools, families and individuals recognize the importance of helping young people with cystic fibrosis. Your creative methods of remembering young people with cystic fibrosis are much appreciated. We will continue to help them — with your assistance. Thank you to all!

Don’t forget that donations may also be made at www.cfanorthdakota.com.
The *Giving Hearts Day* fundraiser on February 14, 2013, Valentine's Day, was designed as such because it represents an opportunity for people to express their love and admiration for those they have encountered in their lives. Those giving to CFA during that event took advantage of the opportunity to express their love and admiration for those in their lives and in the CFA family by donating. Thank you for acknowledging and respecting them and/or their memory.

### Memorials

- Tim & Rhonda Dockter in memory of Harry Dockter
- Roger & June Dahnke in memory of John Ramirez
- Roger & June Dahnke in memory of Ilene Lien
- Viola Schumacher in memory of Frank Mattern
- Mary Mattern in memory of Frank Mattern
- Ron & Anne Erickson in memory of Tom Mattern
- Mary Mattern in memory of Tom Mattern
- Marjorie Johnson in memory of Tom Mattern
- Donna Fricke in memory of Tom Mattern
- Dean & Sylvia Fatland in memory of their daughter, Jan
- Tom & Donna Haustveit in memory of Bonnie Frisinger
- Tom & Donna Haustveit in memory of Larry Rosencrans
- Tom & Donna Haustveit in memory of Vivian Herfindahl
- Don & Pat Sillerud in memory of Vivian Herfindahl
- Dean & Sandy Swenson in memory of Harold Rud
- Dean & Sandy Swenson in memory of Darlene Fine
- Dean & Sandy Swenson in memory of Eileen Younger
- Dan & Phyllis Lien in memory of Pearl Lien
- Pam Wohlwend in memory of Pearl Lien
- Pam Wohlwend in memory of Alfred Lien
- Bob & Tamie Aberle in memory of Tim Wentz
- Janice Bosch in memory of Sonia Balliet-Heidenreich
- Gena Blaine in memory of Sonia Balliet-Heidenreich
- Mark & Bridget Belter in memory of Sonia Balliet-Heidenreich
- BJ & Sarah Knutson in memory of Sonia Balliet-Heidenreich
- Jill Sinner in memory of Sonia Balliet-Heidenreich
- Anonymous in memory of Ryan Thorson
- Anonymous in memory of Brian W. Austin
- Scott & Marci Julson in memory of Mom, Dad, Pa, Grandma J.
- Scott & Marci Julson in memory of Paul Pietsch
- Kelsey Nogosek in memory of Samantha Smith
- Mary Erman in memory of Peter & Alan Allmaras
- Roger & Debby Barth in memory of Howard Huntley

### In Honor Of

- Michele Kramlich in honor of Cierra Horning
- Ann Ellefson in honor of Addie Zimmerman
- Mike & Jessica Zimmerman in honor of Addie Zimmerman
- Sara Bashus in honor of Addie Zimmerman
- Cari Frisk in honor of Addie Zimmerman
- Jan Bashus in honor of Addie Zimmerman
- Tom & Carolyn Hesford in honor of Karen Cossette
- Brandy Randall in honor of Logan Grace Hahn
- Cindy Belohlavek in honor of Logan Grace Hahn
- Chris & Nicole Hahn in honor of Logan Grace Hahn
- Mike & Val Cossette in honor of Ryan & Lily Stroup
- Jen Stroup in honor of Ryan & Lily Stroup
- Bonnie Haupt in honor of Jamie Haupt
- Jim & Kathy Rumple in honor of Jamie Haupt
- Mary Jane Thompson in honor of Carly & Cindy Buchanan
- Renae Gall in honor of Ashlee Rudolf
- Diann & Scott Rudolf in honor of Ashlee Rudolf
- Shelly Goroski in honor of David Goroski
- Angela Glass in honor of Katie Gross-Wangler
- Rita & Tony Wangler in honor of Katie Gross-Wangler
- Rob & Carlotta Schwartz in honor of Nicole Schwartz
- Brad Clemenson in honor of Maria Wharam
- Jeff Feller in honor of Marci Julson
- Michelle & Don Murray in honor of Kyle Hardy
- Dave & Cindy Buchanan in honor of Carly Anne Buchanan
- Jamie Haupt in honor of CF Warriors past, present & future
- Anonymous in honor of Shawna Gackle & Tarah Gackle-Post
FDA OK’s New Antibiotic Form for CF Use

By Cole Petrochko, MedPage Today Staff Writer

WASHINGTON – The FDA has approved an inhalable powder formulation of the antibiotic tobramycin to combat Pseudomonas aeruginosa infection in patients with cystic fibrosis.

The TOBI Podhaler – a plastic inhaler that dispenses the powdered tobramycin – is used twice daily for 28 days followed by a 28-day treatment vacation before starting again, the agency noted in a statement announcing the approval.

P. aeruginosa can cause chronic lung infection that can result in severe long damage over time. In cystic fibrosis patients, the bacteria is traditionally treated with antibiotics administered through a nebulizer. The TOBI Podhaler “is the first dry powder antibacterial drug delivered with a handheld dry powder inhaler,” Edward Cox, MD, MPG, director of the FDA’s Office of Antimicrobial Products, said in the statement.

The drug received a recommendation for approval with a 31-to-1 vote by an FDA advisory panel in September 2012, in spite of earlier concerns related to the product’s safety and efficacy, as well as a prospective concern that adverse coughing events may spread the bug the drug was meant to treat.

Efficacy was established in a randomized, placebo-controlled 95-patient study of adults and children with cystic fibrosis and P. aeruginosa infections. The researchers measured improvement of lung function in treatment compared with a placebo group. All patients received tobramycin treatment following the randomized period of the trial.

Patients treated with the inhalable tobramycin had a significantly improved forced expiratory volume in 1 second of 12.5% versus 0.9% with placebo treatment.

Adverse events included cough with or without phlegm or mucus, hemoptysis, lung disorder, shortness of breath, fever, mouth and throat pain, dysphonia, and headache.

The drug is marketed by Novartis.

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