



# Our Voice

## Central Ohio Chapter President's Article -- Sheri Nash

Our Voice, a newsletter of the Huntington's Disease Society of America, Central Ohio Chapter, is published four times annually to provide information and to relay items of interest to individuals with HD and their families, health care professionals and interested friends and supporters.

I have a daughter who is considered "special needs." Simply put, that is a catch all phrase for so many things. It could mean something related to adoption, or a child with developmental delays, cognitive concerns or a child needing some type of therapy. In Gracie's situation, she has a Neuromuscular Disease. I suppose I could say she's "special needs" because of each of the reasons I have listed- they all apply. Every day, Gracie and I head off in the morning to one of her therapies or to her "special needs" program. Every day, I remind myself to smile because she is making improvements, because she has brought such light into my life and because she teaches me something wonderful every single day. Every day-something new, I just keep saying those words over and over to myself...

Recently, I've acquired a new friend named, Carrie. She, too, has a child with special needs. As we sit together waiting for our sweet babes, we have become friends. Last week, she asked my about my career. I gave my stock answer of raising 4 girls and, "Oh, I do charity work for Huntington's Disease." Thus, started a new wave to our conversation. She wished she could get more involved in her specific charity but just couldn't find the time. There are a few events, but they're really still in the budding phase. She was amazed at what our chapter has done in so little time. Carrie actually made me feel the best by saying she was inspired by our group! Wow! Inspired?!

We then discussed the nuances of having 1 or more genetic diseases in our family. Did it

make us fight? Is there a lot of guilt? Have we always been so open? Has our family been able to draw closer because of these illnesses? Or been torn apart? Has the risk of HD made my parents have any different feelings about their life choices? We ended about talking non-stop for almost two hours. We compared notes, supported each other and, I'm not ashamed to admit, shed a few tears. Carrie simply wanted to learn more about HDSA. I wanted her to feel as excited about making a difference as I am.

Sometimes, I find myself wondering about the odds of having a Neuromuscular Disease and HD in the same family. Sometimes, it brings a serious pang to my heart, but most of the time I just shrug my shoulders- it is what it is. Later that night, Carrie emailed me the Top 10 Reasons to Give Thanks for Your Child with Special Needs. Reading them that day, I started to see that I could replace "special needs" with Huntington's Disease and we could identify a few qualities of those living the day to day life of HD.

Allow me to list a few:

- \* Every day is a learning experience. Some days it's a pop quiz, some days it's a crash course, but living with HD is always an education, for sure.

- \* You meet a better class of family in waiting rooms and support groups. HD gives you entry into an exclusive club of people who are sensitive, sarcastic and sure of their priorities.

- \* Your blessings will always be counted. Other families may take



their gifts for granted. Not you. Not ever.

Please, please remember all of your blessings. They might come in small, less noticeable ways. Yet, hopefully, each of us can find many things to be grateful for and continue to embrace this wonderful time of year. This time of celebration and new beginnings; this time of giving thanks for what we've been given. Throughout this newsletter, we've identified a few of our new beginnings- Golf Outing, Marathon runners, Sand Volleyball, new donors and new volunteers. These are just a few of the things that I am thankful for... that, and the fact that I am officially part of an elite group of people who are sensitive, sarcastic and sure of their priorities.

Happy Holidays

Sheri Nash  
Central Ohio Chapter President

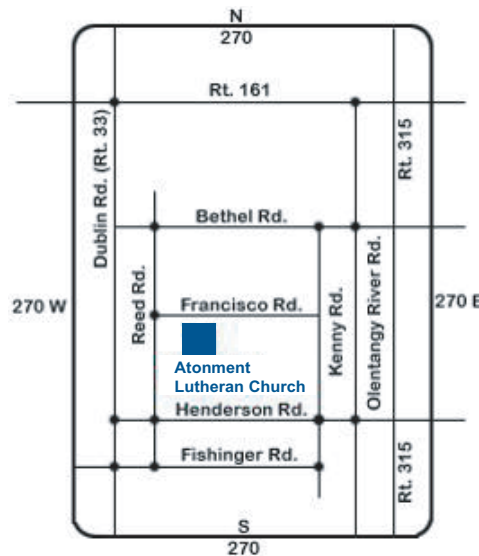
## Ohio Chapter Meeting Times & Places

### Central Ohio

Our meetings are held at 7:00 p.m. on the second Thursday of each month at:

The Atonement Lutheran Church  
1621 Francisco Road  
Columbus, Ohio 43220

Please join us at our next meeting. We first get together, discuss upcoming events and make announcements, then divide into 3 groups: caretakers, "at risk," and persons with HD. Each group has its own challenges and it is helpful to talk to others in the same situation. If we have a speaker scheduled, we stay together. There are two basic reasons to attend support meetings. One is to GET HELP. The second is to GIVE HELP. When you lose a loved one or they go into a nursing home, the usual feeling is that you want to distance yourself for a time. You really deserve some "time off" after care giving. But after awhile, please consider coming back--you can be a great help to people just starting on the road you have traveled. No teacher is as helpful as experience and the lessons you learn one by one can mean an easier time for new caretakers.



*"Any change, any loss, does not make us victims. Others can shake you, surprise you, disappoint you, but they can't prevent you from acting... from taking the situation you're presented with and moving on."*

*No matter where you are in life, no matter what your situation, you can always do something. You always have a choice and the choice can be power."*

*-- Blaine Lee, The Power Principle*

### Teen Support Group

We are planning to reestablish the Teen Support group. Any teenager between the ages of 10 – 18 are encouraged to attend. Meeting time is 2:00 p.m. on Sunday afternoon every other month at Atonement Lutheran Church on Francisco Blvd. Parents are welcome to stay and meet with each other while the teen group is in progress, approximately 1 ½ hours.

This is an important group in our HD family. We want to meet the needs of our young people through group support, information, education, and socialization with other teens who understand.

This group is facilitated by Barb Heiman, Social Worker. Please call 614-292-9960 if you have questions or are interested in attending.

### Akron

Meetings are on a Monday or Tuesday, based on the availability of a meeting room. Ellet Community Center, 2449 Wedgewood Drive, Akron, OH 44312. For questions, contact Wes Johnston (Family Services Chairman) at 330-283-0109. Please see the website for more information: [www.lkwdpl.org/hdsa](http://www.lkwdpl.org/hdsa)

*"You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face." -- Eleanor Roosevelt*

### Cincinnati

This caregiver group meets every third Saturday at 11 a.m. in the Drake Hospital. For the patient and At-Risk groups call Mary Beth Bialic at 513-741-4372.

### Toledo

Toledo group meets every third Sunday from 2-4 p.m. in the fellowship hall at Our Savior Lutheran Church, 2820 W. Alexis Rd., Toledo, 43613. For more information, please call Robin VanGorder at 419-691-8940.

### Dayton

This support group meets at 7:30 p.m. on the second Wednesday of every month at Fairview Methodist Church (on the corner of Fairview & Cataba). For more information please call Cincinnati Chapter Social Worker, Mary Beth Bialic at 513-741-4372.

### Would you like to participate in an Huntington's Disease research study?

Researchers are looking for participants in COHORT – Cooperative Huntington's Observational Research Trial. This study's purpose is to collect information in order to learn more about HD, potential treatments, and plan future research studies of experimental drugs aimed at postponing the onset or slowing the progression of HD.

For more information contact the HSG at 1-800-487-7671 or [www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org) or visit the Huntington Project web site at [www.huntingtonproject.org](http://www.huntingtonproject.org).

## HDSA National Toast



On December 2 all over the United States, friends and supporters of HDSA gathered in various homes and locations to celebrate and raise their glasses in an official "Toast" to those touched by Huntington's Disease. We were able to raise awareness as

many new people were introduced to Huntington's Disease in a relaxing and upbeat atmosphere. In Central Ohio alone, 3 parties were hosted with old and new friends. A wonderful toast was given at each party recognizing the valued contributions of so many people. This event was rolled out by the National office and all of our Chapters look forward to the 2nd annual National Toast. It was a wonderful way to celebrate the holidays as well as commemorate the contributions of so many to HDSA.

## Teen/Tween Event

**ANY TEEN (AGES 10 to 18) INTERESTED IN ATTENDING THIS SPECIAL EVENT PLEASE CALL.**

### What:

Overnight tween event! Includes food, entertainment, friendship, waterpark and overnight accomodations.

### Start Time:

Saturday, February 10, 2007 at Noon

### End Time:

Sunday, February 11, 2007 at 2 p.m.

### Where:

Fort Rapids in Pickerington, Ohio

### Cost:

FREE

### Registration:

Gary Nash at (614) 292-9960 at [nocashnash@sbcglobal.net](mailto:nocashnash@sbcglobal.net) or Marley Moorman at [Sunnychick30@yahoo.com](mailto:Sunnychick30@yahoo.com) or (614) 581-6851.

## Columbus Marathon

In October 2006, Rachel Margo and Laurel Helber participated in the Columbus Marathon in honor of a dear friend. They raised over \$2,100 for HD research. Laurel said, "Rachael and I would do this all over again for any cause forth fighting for... thank you for supporting this cause... because of special people like you some day there will be a cure for Huntington's Disease.



Photo: "CURE HD" shirts





## Care and Compassion in Northwest Ohio

The recent successful fundraising benefit for Huntington's Disease in Northwest Ohio gives us the opportunity to review the growth and development of Huntington's research, education, and clinical care at the University of Toledo College of Medicine, formerly the Medical University of Ohio. There is a great working relationship between the clinical staff and the local Huntington's Disease Support Group, both of which maintain a close affiliation with the Central Ohio Chapter.

In 1998, Dr. Lawrence Elmer, M.D., PhD. joined the faculty in Toledo and established the Parkinson's Disease and Movement Disorder Program. Prior to his

*...this small band of experts has given new opportunities for almost a hundred people throughout Northwest Ohio to deal with this disorder in a more successful manner.*

arrival in Toledo, Dr. Elmer had worked at the University of Michigan, where he completed his neurology training as well as a fellowship in Movement Disorders. Movement Disorders is a subspecialty in neurology that encompasses everything from Parkinson's disease to Huntington's disease and everything in between. While at the University of Michigan, Dr. Elmer had the opportunity to work with some of the world's leaders in Huntington's disease, notably Dr. Anne Young and Dr. Jack Penney. He also worked closely with Dr. Roger Albin. He had close contacts with the Michigan Chapter of the HDSA and served on their scientific board. He also served on the scientific board on a national level for Huntington's Disease Society of America. Needless to say, once he arrived here, he was enthusiastic about developing a comprehensive program for people with Huntington's throughout Northwest Ohio.

The program really took off in 1999 when Kristen Schuchmann joined the Movement Disorder team. Kristen is a licensed social worker and she wholeheartedly embraced the challenge of learning all about Huntington's Disease, working with families, friends, and patients throughout this area. In the last seven years, she has attended numerous national conventions, led workshops, counseled patients and families, and trained other healthcare workers in the subtleties of dealing with Huntington's.

Another breakthrough occurred about four years ago when Colette Gaba joined the team as a genetics counselor. This allowed the development of a pre-symptomatic screening clinic for people who are at risk of Huntington's but did not yet have any symptoms.

While there are many other individuals involved in the care of people and their families with Huntington's, suffice it to say that this small band of experts has given new opportunities for almost a hundred people throughout Northwest Ohio to deal with this disorder in a more successful manner. The challenges of Huntington's are quite numerous, but many advances have occurred with regard to medications that help treat the symptoms as the disease advances. In addition to Dr. Elmer, Kristen, and Colette, there are three other nurse practitioners, a physician assistant, speech pathologists, physical therapists, occupational therapists, neuro-psychologists, and psychiatrists who are involved in this comprehensive program.

The clinic is located at the University of Toledo College of Medicine Rupert Center, between Glendale and Arlington in Toledo. Patients and/or their families can obtain additional information about the Huntington's program by calling Kristen at 419-383-6737. It is anticipated that new clinical trials for Huntington's will be available within the next year.

## www.HDSACentralOhio.org

Check out our website at [www.hdsacentralohio.org](http://www.hdsacentralohio.org) for more information on our fundraising events, board meetings, and the latest research.

While you are there, be sure to check out how easy it is to donate online. You can donate in memory or honor of a loved one, purchase HD products, amrayllis bulbs, and even bid on items on our Ebay site!

### *"A journey of a thousand miles starts with just one step."*

A gentleman named Eric who has no affiliation with HD, other than being a friend of someone at risk, is planning to Climb Mt. Rainier in August 2007 to raise money and awareness of HD!

On his personal fundraising page, he states, "This is my first step. To me it was clear that I could make a difference, I could help bring awareness of this disease."

Help sponsor his climb online at: <http://www.firstgiving.com/ericlicht>



## Chapter Memorials and Honorees

### In Honor of

#### Gary Nash & Family

Donald & Virginia Harris  
Dawn & Jeff Caldwell  
Sandra Bustin & Michael Reyes

### In Memory of Gloria Hornbeck

Delores Meeker  
Geoffrey Hornbeck

### In Memory of Christy Neuberger

Dolores Meeker

### In Memory of Marge Devault

Dolores Meeker

### In Memory of Lawrence Meyers

The Ohio Toy Company  
Norman & Lori Baldwin  
James & Betty Kerr  
Carolyn Leindecker  
Eric & Linda Damman  
Lee & Sarah Rupert  
Eldor & Jane Gerken  
Kenny & Marsha Drewes  
Alan & Kathy Damman  
Bill & Bert Bremer  
Wick & Joanne Miller  
Jeff & Betty Marihugh  
Gary & Jamie Bostelman  
Ken & Kae Gerken  
Rod & Jeri Bostelman  
Art & Pat Michaelis  
Geri Haase  
Tony & Cathy Aschemeier  
Bill & Judy Haase  
Loren & Patsy Wachtman  
Dave & Julie Sanders  
Esther Bowersox  
Esther Sonnenberg  
Todd & Chris Behnfeldt  
Mr. & Mrs. Dave Helberg  
Dave & Heidi Aldeman  
Dennis & Teresa Sonnenberg

Bob & Karen Weber

Carl & Irma Gerken

Keith & Carol Sonnenberg

James & Judy Moom

Carolyn Bauers

Mr. & Mrs. Norm Sonnenberg

Ott & Helene Meyer

Eldon & Elaine Meyer

Joe & Jane Meyer

Phil Meyer

Pete Scheele

Mr. & Mrs. William Behnfeldt

Ron Van Dine

Gary & Hallie Van Atta

Phil & Denise Hornish

Jerry Boyd

Jan McQuillan

Mark & Cathy Richardson

Rick & Danie Budde

Chuck Kreinbilh

John & Rose Lymanstall

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Mark & Kathy Meyer

Brett & Michele Meyer

Russell & Elaine Meyer

Jason & Amy Lieb

Dexter & Janis Benecke

Lester & Lois Boulton

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Mrs. Dorothy Honemann

Mr. & Mrs. Steve Lieb, Andy & Liz

Mrs. Emilie Gerken

Mr. & Mrs. Kenneth Drewes

Mrs. & Mrs. Edwin Gerken

Mrs. & Mrs. Dan Witte

Mrs. & Mrs. William Behrman

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Mr. & Mrs. Ray Schroeder

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Mr. & Mrs. Marvin Gebers

Mr. & Mrs. Wilbur Joost

Mr. & Mrs. Harlan Fry

Mr. & Mrs. Norman Wiemken

Mr. & Mrs. Norm Lange

Ms. Norma Drewes

Mr. & Mrs. Dexter Benecke

Mr. & Mrs. Burdette Rathge

Mr. & Mrs. Roger Mahnke

Mr. & Mrs. Ted Garmyn

Carmen & Barb Wiechers &

Carolyn Schlade

Mr. & Mrs. Loren Plassman

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Mr. & Mrs. Darwin Sonnenberg

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Miss Tena Benhfeldt

Mr. & Mrs. Tom Beck & Family

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Mr. & Mrs. Dennis Helberg

Mr. & Mrs. Robert Tilse

Ms. Mildren Nagel

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Craig & Candace Franz



### 1st Annual 2007 HDSA Sand Volleyball Tourney

The first annual Sand Volleyball Tournament will be held at Flannagan's Dublin on July 21st, from 9-5. Don't forget to tell your friends, family and co-workers about the Cornhole Tournament that will be going on in the afternoon! The \$250 entry fee will cover teams of 10, with 6 on a court. Prizes to the top 4 teams! Food and Drinks will be available. Come on out to Flannagan's and have a fun time in the sun! All proceeds will be used for the treatment, care, and cure of those affected by HD!

Any interested participants or volunteers, please contact Theresa Hanson at 614.539.0055 or [theresa\\_hanson@sbcglobal.net](mailto:theresa_hanson@sbcglobal.net).

## Golf for a Cure

October 15, 2006 was a beautiful and brisk day for a new Central Ohio golf outing. Over 40 people gathered to play at Willow Run Golf Course in Alexandria, Ohio with food and drinks included. Lunch and dinner were supplied and many golfers found that they could simply "swing" by in between holes to pick up any needed supplies. It was amazing to see all of the support from newcomers to our charity come from all over the state.

Many of the players were there to support, Larry and Daleena Brown, Chairpersons of the event. This golf outing was an introduction for them to HD and more than a few of the attendees look forward to coming back again. Many thanks go to Oraletta and Joe McCoy for their very skillful expertise with the food and drinks for the day. Everything was simply perfect.

This event was extremely successful with door prizes, 1st, 2nd and 3rd place prizes as well as a Loser's prize. Many companies supported the event by sponsoring holes and donating items. We look forward to a second round of this event which raised over \$4000 for Central Ohio HDSA. Congratulations to Larry Brown and his entire family for a wonderful event.



## Family Festival to Cure HD

The Toledo Area Support Group held its second fundraising benefit for HD on Saturday, October 28, 2006. We were fortunate enough to host the event at VFW Post #3013 in Holland, Ohio again this year. The Post graciously donated the use of their spacious facility! The focus of our event, inspired by Woody and Marjorie Guthrie, was to create a lively, fun, family oriented event to raise awareness of HD and to raise money for research and family services! We are quite proud that we were successful in doing both! The efforts of a large dedicated group of people in Northwest Ohio worked closely together to plan this benefit – many of whom have no affiliation with Huntington's Disease other than the desire to help with an important cause. We are truly grateful for their generosity in spirit and in action!

This year's event included a lot of activity which was expertly announced throughout the day by our Master of Ceremonies, the Honorable Timothy Wagener, the Mayor of Maumee, Ohio. Our wonderful cooks served hot sandwiches and salads along with soft drinks, coffee and beer. We had a chili five person cook-off that was a lot of fun and quite delicious. Many friends and family donated baked goods for the free-will donation bake sale. Many folks who joined us won one of dozens of door prizes that were awarded continually



during the benefit.

"Happy the Clown" entertained children of all ages and many enjoyed the snow cones that were served. Over 100 items were donated for silent auction and several merchandise and 50/50 raffles were held throughout the day. Doug Upell, again, donated a whole hog to be raffled – in which we included the meat processing! We enjoyed the music of the Bobby May Band and Jimmy Forrest and Family all afternoon and evening. Then, Dirk Meyer and his energetic crew held an exciting live auction of over 70 items of beautiful merchandise!

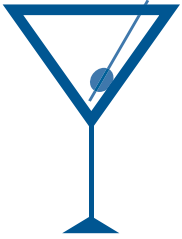
During the afternoon, Shane Schmidt, a friend of an HD family, offered a fund-raising challenge to the crowd: "If you raise \$500.00 now and I'll let you shave my head! If you raise \$1000.00

you can shave it into a Mohawk haircut – and I'll keep it until Thanksgiving!" The generous folks in attendance came through and donated \$1019.00! An eager group of friends shaved Shane's hair into a beautiful Mohawk – with the accompaniment of the fiddle player from Jimmy Forrest's band!

In the weeks previous to the benefit, a group of volunteers sold a large number of Home Interiors Scented Candles as a fund raiser – and presented a check of over \$850.00!

The support from friends, family and the entire community was overwhelming – we estimate that nearly 400 people attended! And through the tremendous efforts of a great number of dedicated and hardworking volunteers we were able to raise a total of \$12,000 for this year's benefit! Many heartfelt thanks to members of the benefit committee including: Ruth Harrison, Sherlyn Lulfs, Gloria Forrest and Lorrie Colton.

We also had a striking image of Woody Guthrie designed by Dan Wilkins of The Nth Degree in Luckey, Ohio – that was used on our advertising posters and is also available on printed t-shirts we have for sale. Kids size Large and Adult Small, Med, Large and XL are \$10.00 – 2XL and 3XL are \$12.00. You may order shirts by contacting Robin VanGorder at [robin@purkeyins.com](mailto:robin@purkeyins.com) or 419-691-8940.



## Annual Fundraiser Presents A Jazzy Evening 'With A Twist!'

This year, the Huntington's Disease Society of America (HDSA) hosted their 6th Annual Celebration of Hope event and raised over \$70,000. This year's "Martini Blast" theme stirred things up! On Friday, September 29th, top business leaders, community officials and other notable guests gathered downtown for one of Central Ohio's premiere charitable events. Masters of Ceremonies, Megan Pringle, of WSYX Channel 6/ WTTE Fox 28 and Billy Aaron Brown, HD National Spokesperson.

The evening began at 7 p.m. at The Vault, as guests sample a bevy of specialty martini cocktails, donated and designed by Three Olives Vodka. Bidding was heavy on the wide selection of silent auction packages including three autographed items: Muhammad Ali boxing gloves, and two guitars that were signed by the Rolling Stones and the other by Jimmy Buffet! Live entertainment, a Tribute to Frank Sinatra and friends, was preformed by Michael Sutherland, entertainer.

Before night's end, a special moment was taken to honor The Elsie Znamenacek Family, as our HD Humanity Award recipients. The Corporate Leadership Awards went to Mickey Halls of Rich Products for leading this campaign. They demonstrated again, the compassion of friendship and the importance of giving.

An official after-party took place at Spice Restaurant & Lounge allowing guests a VIP access to the venue beginning at 10 p.m. Spice was a fun and "happening place" to be!

A very special thanks go out to our Gold, Silver and Bronze sponsors for whom we would not be able to keep the doors of the HDSA Center of Excellence open without their support.



Top Photo: Znamenacek Family,  
HD Humanity Award Recipients



Left Photo: Mickey Hall, Corporate  
Leadership Award Recipient

Our Gold Sponsors are: Computer Associates, 3 Olives Vodka, Spice Lounge, WWCD 101.1FM, The Cullman Family, Maxine Vaughan and The Marty Vaughan Family. Our Silver Sponsors: Wayne and Paula Harer, Rich Products and T. Load Specialties, Inc. Our Bronze Sponsors: Frank and Linda Kass, Bob Evans Restaurant, The Martin/Hickey Families, Check Point Software Technologies, LTD, Digital Interiors, EMC Corporation, Gary and MaryAnne Nash, Network General, Dorothy Vaughan, Virtusa Corp, The Robert Weiler Company.

The evening was truly a BLAST!!! It was a real CELEBRATION that HOPE is in our future. We hope that EVERYONE will mark your calendars for next years "Celebration of Hope" Martini Blast! September 28, 2007!

## 2007 Calendar of Events

February	Teen/Tween Event
March	Texas Hold'em Tourney
April	Hoop-A-Thon
June	Dream Date Auction
July	Sand Volleyball Tourney
September	Martini Blast
October	Golf Outing
November	Amaryllis Sale
December	Amaryllis Sale



## Texas Hold 'Em

1st Annual Tournament in March.

Interested players or volunteers can  
contact Larry Brown at 614 208-8699.



**HUNTINGTON'S  
DISEASE SOCIETY OF  
AMERICA  
CENTRAL OHIO  
CHAPTER**

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**Would you like to send a donation in memory  
or in honor of someone close to your heart?**

**If so, please send your donation to HDSA,  
Central Ohio Chapter, with an attached note or letter.**

**Please fill out and return this certificate.**

**Name** \_\_\_\_\_

**Address** \_\_\_\_\_

**Phone number** \_\_\_\_\_

**Please direct this donation of \$\_\_\_\_\_ to: Care\_\_\_\_\_ % Research\_\_\_\_\_ %**