

# FISHING



## REMEMBERING THE PAST. LOOKING TO THE FUTURE.

**INSPIRATIONAL DEENA** On March 24th, our friend Deena Tannous died due to FSH related respiratory complications. Deena, shown here with Barry Bonds, was only 26 years old and an inspiration to all who knew her. She will be missed.

Our thoughts go out to her family and her many friends as they cope with the loss of this very special woman.

### INSPIRATION

**YOU DID IT AGAIN!!** Our 4th Annual FiSHing for a Cure Dinner and Auction was held at the Bellevue Hyatt January 26, 2008 — More than \$215,000 was raised during our event!!! Thanks to all of our donors, supporters and our wonderful volunteers. **More inside.**

### HOPE

A 12 week study of **low-intensity aerobic exercise** showed an improved maximal oxygen uptake and workload with no signs of muscle damage in patients with FSHD, concluding that aerobic training is a safe method to increase exercise performance. See **FSHfriends.org** for the full study.

### TAKE ACTION

**Volunteers and donations are needed!** Our Fifth Annual "FiSHing for a Cure" Dinner & Auction will be on February 7, 2009 at the Bellevue Hyatt. The stars will shine as we celebrate five years of your enthusiastic support. See **FSHfriends.org** to learn how you can help.

## FISHING FOR A CURE...



“WITH THE MONEY THAT HAS BEEN RAISED.

### THANK YOU!

OUR FOURTH ANNUAL FISHING FOR A CURE DINNER AND AUCTION was held at the Bellevue Hyatt January 26, 2008. It was a heartwarming night due to the generosity of those attending. More than 275 guests showed great willingness to embrace our mission—funding FSH Muscular Dystrophy Research projects. More than \$215,000 was raised during our event!!! Thanks to all of our donors, supporters and our wonderful volunteers. Our annual fund raising dinner event would not be possible without each and every one of you!! **Together we will make a difference!**



Auction Volunteers — a BIG thank you for all your hard work!

## Our Circle of Friends

Meetings with members of the Friends Scientific Advisory Board were conducted in March to plan how to solicit new research grants. It was decided that a short statement of the research plan and a summary of the study goals would be step one of the process. Step One is now completed. The Board received nine summary FSH research proposals from which five have been selected for further review. We feel that this two-step process has made it easier to attract scientists from a variety of backgrounds to think about FSH and to submit ideas about how they might approach this genetic disorder. We are thrilled to have received such a number of good proposals this year & the final awards will be announced this summer.

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THANK YOU FOR HELPING TO FUND PILOT FSH STUDIES. FUNDING PILOT STUDIES IS AN IMPORTANT STEP IN MOVING A RESEARCH IDEA TO A DEFENDABLE RESEARCH STUDY WHICH CAN APPLY FOR, AND POSSIBLY OBTAIN FULL FUNDING FROM OTHER GRANTING INSTITUTIONS. NEWS REGARDING THE RESEARCH GRANTS AWARDED THIS YEAR WILL BE POSTED ON OUR WEB SITE — [FSHFRIENDS.ORG](http://FSHFRIENDS.ORG)



## WE CAN PUT A LOT MORE LINES IN THE WATER.” JASON

### THANKS TO OUR DONORS

FEBRUARY, MARCH, APRIL & MAY 2008

Kathleen Abrams

Susan & John Braun

Steven & Sue Churchill

Dick & Sandy Eacker

Betty Elsas

Peggy Etchevers

Mary Fobes

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Dennis Shaw & Julie Howe

George Shaw & Lynn Fischer

Jack & Noni Shaw

Jerry Zyskowski & Diane Cook

CORPORATE DONOR

Amgen Foundation

### RESEARCH PROJECTS FUNDED

The Pacific Northwest Friends of FSH have provided tremendous support for new research by funding pilot research projects focused on better understanding the molecular biology of this disease. Only by arriving at this better understanding will advances be made in treatment and prevention. Three research projects have been funded thus far. The funds have gone to Brian Kennedy, Department of Biochemistry, Dr. Dan Miller Department of Pediatrics and Dr. Joel Chamberlain, Department of Medicine (Medical Genetics) all at the University of Washington. The fourth round of funding has begun with 9 project applications submitted for review this spring. This is the largest number of applications in the short history of the organization and each proposed project is of very high quality. We are looking forward to funding additional research. Furthermore, the PNW Friends of FSH supported a highly successful international workshop on FSH research in Seattle last year and there are plans for another workshop in the near future. These events bring together leading scientists to discuss the latest advances and new strategies to solve the FSH puzzle. The Friends can be very proud of the major contribution this organization has made to advancing FSH research. The scientists are very grateful for this support and feel both stimulated and challenged to move the field forward as quickly as possible.

**Dr. Thomas Bird**

*Director of our Scientific Advisory board*

### FRIENDS OF FSH RESEARCH GRANTS

University of Washington \$150,000 • 3 years, \$50,000 per year

Children's Hospital Seattle & Fred Hutchinson Research Center \$100,000 • 2 years

University of Washington \$100,000 • 2 years

University of California, Irvine \$52,800 • '06-'08

### RESEARCH SUPPORT

University of Mons-Hainaut, Belgium \$14,845 • '07

Research Conference \$2500 • Co-Sponsor Dec. '06

### POSSIBLE FACTORS IMPACTING FSH VARIABILITY

**Dear Terry** • I had a great time at the auction and it was nice to meet people suffering with this disease. I also realize I am quite lucky in that I am not terribly affected yet. I think you did such a great job. From discussing things with Ryan (Levinson) and other people one thing I believe with this disease is don't allow your body to go into a catabolic state. (i.e. eat more small meals and don't allow your body to go hungry) Possibly if you are in a hungry state it allows your body to breakdown the muscle cells quicker. I try to drink a protein shake after exercise and I always try to eat something when I first get up. I always try to eat a good breakfast. I know a lot of these things go without saying, but maybe lifestyle, diet, exercise etc. accounts for a lot of the variability this disease presents with. I hope all is well and look forward to helping the cause more this year. I will also forward a study my neurologist sent re exercise and FSHD, Brian (and others) may find it interesting. • Harry, Vancouver, B.C.

# AUCTION FEB 7, 2009

5th Annual FiSHing For a Cure Auction  
PLAN AHEAD! YOU are the heart of the  
Friends of FSH Research, YOU make the  
difference by —

- Donating Items
- Volunteering
- Filling a table

## PLANNING

7 PM All Volunteers Welcome!

17 JUNE 21 OCT Planning meetings  
15 JULY 18 NOV are every third  
19 AUG 16 DEC Tuesday, every  
16 SEPT 20 JAN month

## CONFERENCE

11 JULY FSH research conference,  
12 JULY Seattle WA

## OPEN HOUSE

27 JULY Researchers, volunteers and  
4-7 PM friends

### Mission Statement

"Friends of FSH Research a 501(c)(3) organization is working to impact the lives of those affected by FSH Muscular Dystrophy by financially supporting FSHD research."

### Purpose Statements

1. To encourage, promote and fund increased scientific and clinical research of Facioscapulohumeral Dystrophy, or FSHD.
2. To conduct fund raising efforts and solicit grants and contributions from individuals, private foundations and others, in order to sponsor research to help advance the study and understanding of FSHD, with the goal of identifying treatment and a cure for the disease.
3. To disseminate information about FSHD and encourage additional public support for FSHD research by raising public awareness of the need for more research funding.

### Passion for our Mission

The heart of our mission is people. Through our fund raising we advocate for those that have FSH Muscular Dystrophy. We believe that every human being deserves to have the best quality of life possible. Those living with FSH deserve a better quality of life. We believe that by funding FSH research, those with FSH today and those diagnosed with FSH tomorrow will have a chance for an improved quality of life.

### Our Name Change — "Friends of FSH Research"

What's in a name? Pacific Northwest Friends of FSH Research is now Friends of FSH Research as our mission reaches far beyond our home.

## A MESSAGE FROM TERRY COLELLA, PRESIDENT

*"...you are lucky that FSH is your son's diagnosis."*

Those words were spoken by a doctor at Children's Hospital in Seattle who had earlier in the summer diagnosed Brian to have a muscular "imbalance." When he learned that Brian was diagnosed with Facioscapulohumeral Muscular Dystrophy, or FSH, he came to my office to talk about Brian and told me that Brian was "lucky."

I realize that he meant that Brian was lucky not to have a fatal condition, but "lucky" was far from what we felt when Brian was diagnosed in September 2003.

Facioscapulohumeral Muscular Dystrophy has been poorly understood by those in medicine and is most often unheard of in the general public. The public may know about Muscular Dystrophy but are seldom aware that there are different forms of Muscular Dystrophy like FSH and that the research funding for each varies greatly.

FSH has been a condition simplified in most textbooks as one which affects the muscles of

the face, upper arms and upper back, while the many other impacts of FSH such as a loss of lower leg strength, respiratory complications due to a weak or absent cough, extreme fatigue and chronic pain are not mentioned. The fact that those living with FSH must continually adjust their dreams and goals due to a progressive loss of muscular strength is seldom mentioned.

No, I do not believe Brian should feel "lucky" to have FSH Muscular Dystrophy. But, Brian and our family do feel extremely "lucky" to have a community which has embraced our cause. Together, we have increased the public's awareness of FSH. We have successfully stimulated and funded FSH research studies at the University of Washington. Together we are making a difference!!

I extend my deepest gratitude & thanks to each of you for helping to make a difference for those living with FSH. With your continued support, the future for those diagnosed with FSH tomorrow will be much brighter.

## SPEAK OUT! RESEARCHERS AND FRIENDS

PLEASE TAKE THE TIME TO GIVE US YOUR IDEAS AND SUGGESTIONS. IT IS OUR HOPE THAT THIS NEWSLETTER WILL BE A RESOURCE FOR ALL OF THOSE WHO CARE ABOUT THOSE WITH FSH.

- If you are living with FSH and would like to share your story with our donors and volunteers, we'd love to hear from you.
- If you are a donor, auction attendee, web site reader, FSH researcher, FSH volunteer or curious reader, feel free to submit your suggestions and ideas to us.
- If you would prefer to receive this newsletter digitally, please provide us with your e-mail address.

Your donations are welcome! Go to [FSHfriends.org/Donate](http://FSHfriends.org/Donate) to print out your donation form and send to us in the enclosed envelope. Cars, boats, trailers, resalable items, auction items. If in doubt—Call us.

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