

32 Years of Research, Education & Support

GOOD NEWS for CFRI Research !!

By Jonathan Widdicombe, Ph.D.

Cystic fibrosis is caused by defects in the “cystic fibrosis transmembrane conductance regulator,” or CFTR. This chloride channel is found predominantly in epithelia, the sheets of cells that line all the body surfaces (such as those of the guts and airways) that ultimately have contact with the outside world. As well as providing a barrier between us and the outside, epithelia perform selective exchanges between inside and out. The airway epithelium, for instance, regulates exchange of water, salts and other substances between our blood and the “airway lining liquid,” 1/100th of a millimeter thick layer of liquid on the epithelium’s luminal surface. In cystic fibrosis, it is believed that lack of functioning CFTR in airway epithelial cells alters the volume or composition of this airway lining liquid in such a way as to promote bacterial colonization. Further problems ensue, and the resulting lung disease is the major cause of death in cystic fibrosis.

With this as background, it is not surprising that the Elizabeth Nash Memorial Fellowship Program, and CF research in general, has had two main foci. The first has been on getting functional CFTR into the apical membrane of airway epithelial cells.

The second has been on determining the changes in airway lining liquid that occur in cystic fibrosis. In the seven years of its existence, the fellowship program has funded sixteen fellows in ten different laboratories at UCSF, UC-Davis, UC-San Diego, UC-Berkeley, Stanford and Children’s Hospital Oakland Research Institute. The researchers who

have been awarded fellows through the Program are among the best in the world, and the research performed has been of the highest quality. Fellows have been co-authors on 24 original research articles published in highly prestigious journals.

Fellowships are usually for two years, and at any one time there are four fellows in the Program. Ideally, two new fellows

are recruited every year. However, due mainly to fellowship extensions, all four fellowships are being renewed this year. After comprehensive external review, the following research projects were selected from eight applications: Dr. Ruth Muchekehu will work with Dr. Paul Quinton at UCSD on how bicarbonate (which is transported by CFTR) affects mucus secretion; Dr. Iwona Bucior working with Drs. Engel and Mostov at UCSF will study *Pseudomonas* binding to airway epithelial cells; Dr. Vihas Vasu will work with Dr. Eiserich at UC-Davis on therapeutic strategies to combat oxidative stress in cystic fibrosis respiratory tract secretions; Dr. Monal Sonecha of UCSF will help continue Jeff Wine’s research at Stanford on how airway mucous gland secretions are altered in cystic fibrosis.



Ruth Muchekehu, Ph.D.



Iwona Bucior, Ph.D.

RESEARCH
Your CFRI Dollars at Work



Vihas Vasu, Ph.D.



Monal Sonecha, M.D.

An important function of the Elizabeth Nash Memorial Fellowship Program is to foster interactions among CF researchers. That is why there is a Fellowship symposium at this CFRI Twentieth Annual Education Conference. These colloquia allow the fellows and faculty to present and discuss their findings. Join us!

CFRI NEWS

2007 Summer Issue

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2672 Bayshore Parkway, Suite 520,
Mountain View, CA 94043
Phone: (650) 404-9975
fax (650) 404-9981
E-mail: cfri@cfri.org
Web site: www.cfri.org

Editorial Chief

Carroll Jenkins

Assistant Editor

David Soohoo

Contributing Writers

Carroll Jenkins
Ana Stenzel

Jonathan Widdicombe, Ph.D.

Layout/Illustration and Design

Kathy Mitchell

Photography

Craig Burleigh

Audio/Visual

Scott Wakefield
Frank Flynn

Website Development

Bob Benz

Accounting/Bookkeeping

Scott Hoyt and Kim Young

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Notes from the Executive Director

As our August events draw near, excitement builds in the CF community. Check the calendar below, visit our website (www.cfri.org), and give us a call for more information!

Our 20th Annual Education Conference brings attendees and renowned speakers from across the country who have an interest in a broad spectrum of CF issues. Join us for this outstanding opportunity to talk with the experts.

Our front page article by Jonathan Widdicombe introduces you to four new and exciting research projects funded by CFRI. Come hear first hand about these on Saturday, August 11. Other recently funded CFRI projects will also be shared. Come learn about the research your dollars support!



Carroll Jenkins,
Executive Director

Walk through our Gallery of Stars: a photography display of CF community members from far and near. Celebrate the launch this month of CF Newborn Screening in California.

Our Teen and Adult Day Retreat this summer will be very special. At Vallombrosa, guests have the chance to unwind, play and learn from each other. From speakers to skating, we have a lot of fun opportunities planned.

Fundraisers in the local community and across the country contribute to these important events. In this issue of *CFRI News*, read about a special golf tournament held in memory of Kelly Colgan. Other events that have taken place include golf tournaments such as "The Tomato Classic" produced by Vernon Schmall in Modesto, and a benefit hosted by Legends and Heroes in Concord, CA.

The Altanos in Santa Cruz held their annual July 4th barbeque, Corey's Walk was organized once again by Jean Sarkis, and Cathy Toresdahl hosted the Hawaiian Tea.

Finally, meet Clare Webster's family on page 5. An adult with CF, she and her husband Justin welcome their new little one, Jason Paul Webster.

Many of you volunteer for our Mothers' Day Tea, serve on our Board and on our Committees, help in the office, and create fundraisers that support CFRI. Pharmaceuticals and Foundations are sponsors of our events. In all of these ways, you help our organization grow to meet the needs of the CF community.

We thank you all – so very much!

Warmly,

Carroll Jenkins
Executive Director



AROUND THE CORNER

2007 Calendar of Events



August 5-10, 2007

CFRI TEEN & ADULT DAY RETREAT

Staying Alive: 1970's Disco!

Vallombrosa Center - Menlo Park, California

August 6, 2007

CFRI BENEFIT 23rd ANNUAL GOLF TOURNAMENT

Cinnabar Hills Golf Course – San Jose, California

August 10-12, 2007

CFRI 20TH ANNUAL EDUCATIONAL CONFERENCE

In it to Win It: Successful Strategies for Living Well with CF

Sofitel San Francisco Bay – Redwood City, California

October 24, 2007

CFRI GENERAL MEMBERSHIP MEETING

Lucile Packard Children's Hospital, Palo Alto, California

Family of Kelly Colgan Holds Benefit Golf Tournament for CFRI Teen and Adult Day Retreat

By Ana Stenzel

The family of Kelly Colgan, long time CFRI summer camp and retreat attendee, held their 15th Annual Kelly Colgan Golf Classic on April 29, 2007 in Fresno, California to raise funds for the CFRI Teen and Adult Day Retreat, which will be held August 5-10, 2007. Kelly Colgan, who had cystic fibrosis, grew up in Fresno, California but moved to Seattle at the age of 15. She passed away from cystic fibrosis on June 13, 2003 at the young age of 20.

The Kelly Colgan Golf Classic has been held annually since 1993 as a benefit for CFRI. The golf tournament is coordinated by Kelly's mother, Cindy Colgan, and her sister, Kristy Collins. The family chose CFRI as the benefit organization because of the assistance that CFRI provided them during Kelly's life. The golf tournament is sponsored by Cindy Colgan's business, Lancer's Bar and Grill, which is located in Fresno, California.

In April, sixty golfers attended this year's Tournament at the Sherwood Forest Golf Club in Sanger, CA. The day began with breakfast, followed by all-day golfing in a scramble-type tournament. The day concluded with a BBQ dinner. Prizes were provided for 1st, 2nd and 3rd place, closest to the pin, and longest drive. There was also a live auction and raffle, with items donated from local businesses. Volunteers helped the Colgan family during this exciting event. The highlight of the auction this year was a classic moped, auctioned off for \$1200!

The Tournament raised over \$4000 for the CFRI Teen and Adult Day Retreat, surpassing their revenues of the past four years. This additional funding is available to assist with travel expenses and hotel accommodations for Retreat attendees. Kelly, who last attended Retreat in 2002, shared with her family how important the week at Retreat was for her. In previous years, she was unable to attend because she could

Kristy Collins



not afford the travel costs from Seattle. Prior to her death, Kelly requested that her family continue the golf tournament as a fundraiser for Retreat so that more people with CF could benefit from it the way she had. According to Kristy Collins, Retreat provided Kelly with the "refueling" she needed to get through her year. Kelly believed that Retreat provided people with CF a great tool to help them cope with their everyday lives and to be among others who really understood

their challenges.

The annual golf tournament helps the Colgan family keep Kelly's spirit alive. Kelly was strong, determined, and assertive with her healthcare providers, and never let her illness stop her from doing what she loved. She attended Bellevue High School where she was co-editor of her high school yearbook, and was named the best speaker in her mock-senate club. At the time of her passing, she was a sophomore at Western Washington University in Bellingham, Washington, where she was majoring in communications. Kelly had friends from all over the world and had an impact on everyone who knew her. She is deeply missed and fondly remembered by everyone at the CFRI Teen and Adult Day Retreat for her laugh, her positive spirit and her unforgettable smile.

Leon Ferguson and Cindy Colgan



In Honor of *(From October 1, 2006 to May 31, 2007)*

"In Honor of" lists names of living persons in whose honor a donation has been made. Do you have a relative or friend whom you would like to celebrate/salute? Are you searching for the perfect birthday present, wedding or anniversary gift, graduation gift, etc.? Give a gift with lasting impact – make a donation to **Cystic Fibrosis Research, Inc.** At your request we will send a special message to the recipient informing him/her of your contribution. Your donation not only recognizes your loved one's special occasion; it benefits children and adults with cystic fibrosis and their families as well. Mail your contribution with the name, address, and the occasion for the person you are honoring to: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043.

Dr. John Whalen's Patients	Larry Clark	Daniel Ellett	Dr. Jean Hanley	Kristine Jones
Chelsa Aboud	Ryan Coelho*	Brennan Emerald	Will Harbison	Laine Jones
Claire Alexander	April Cogdell	Traci Emerald	Julianna Harding	Mary Jones
Adam Aliotti	Eva Cohen	Travis Emerald	Monica L. Harding	Michelle Jones
Gianna Rose Altano	Sean Collins	Audre Estournes	David Hardy	Peggy Jones
Sydney Altano	Lauren Colonna	Janelle Estournes	Kathy Hardy	Kaiser Santa Teresa
Sadie Anderson	Ann Colten	Tommy Evans	Mckenna Hardy	- Infusion Nurses
Dan Applebee	Eliza Colten	Sebastian Fabricius	TJ Hardy	Alex Karwowski
Isabelle Applebee	Mr. and Mrs. Richard	Hilda Falco	The Hardy Family	Kelly Haga's Children
Michele Applebee	Colten	Billy Federal	Brandan Harrigan	Marie Kennedy
Jessica Arvidson	Michelle Compton	Alanah Fink	Kerry Harrison	Jeremy Kharrazi
Lindsay Bachtel	Allison Conway	Jarrold Fischer	Alissa Harvey	The Kharrazi Children
Haleigh Baker	Michael Conway	Victoria Ann Flamenco	Tanner S. Harvill	Edward Kinney
Jaimee Baker	Nicholas A. Cook	Kate Fleming	Barbara Harwood	Kay Kinney
Kyle Baker	Cameron Cornell	Kathleen Flynn	Stacy Hawes Melle	Lori Kipp
Pearl Baker	Scott Cortes	Ryan Foster	George Hawley	Bridget Klein
Lucy Barnes	Lavergne Cowden	Scott Foulger	Deane Hawley	John Klein
Jamie Barry	Dave Cowden	Jacob Fraker	John Hawley	Juana Klein
Makinnon Baugh	Cheri Cowden	Joseph Fraker	Christian Heavner	Eleaschia Kobi
Marin Baugh	Denny Cowden	Elena Francois	Tyler Heavner	Bill Kolchin
Mikele Baugh	Robert Cowden	Bernie Fredrick	Abigail Heilman	Eleanor Kolchin
The Baugh Family	Trevor Cowden	Rhonda Fredrick	Max Heilman	Phillip Kolchin
Maggie-Faye Bendz	Laura Cramp	Emily Fredrick	Tori Hendricks	Jason Konkel
Brett Bennett	Ed Cramp	Jessica Fredrick	Leland Herring	Michael Kozlowski
Amanda Bergman	Barbara Curry	Linda Gagnon	Anthony Hidalgo	Santosh Krishnan
Pat Berndt	Jim Curry	Jim Galla	Jeremiah Holdaway	Tiffany Kuehl
Allison Best	Jason Dadami	Marion Galla	Joshua Holdaway	Steven Kusalo
Andrew Bianco	Ashley Davila	Sean Gallagher	Drew Hotson	Susan Lane Hoffman
Charlie Bianco	Gayle Davis	Natasha Gaziano	Sarah Housman	Timothy Laufenberg
Patricia Bianco	Lori Davis	Debbie Gerow	Katrina Howell	Stacey Lawn
Douglas Bianco	Michael Davis	Mark Ellis Gerow	Phillip Howell	Kody Lawrence
Susan Bianco	Olivia Davis	Jenise Giuliano	Erinn Hoyt	Dylan Leaphart
Aidan Biggar	Matthew DeGregory	Larissa Giuliano	Clark Huddleston	Alysa Lenart
Oliver Biggar	Gordon DeVore	Ashleigh Godfrey	Bill Hult	Barbara Lenssen
Francine Bion	Alice Dillon	Rosalyn Goldman	Colleen Hunt	Carly Lindmeier
Rebecca Boyer	Bev Donelson	Jennifer Goodwin	Isabel Huntsinger	Rose Logue Harting
Brian Burks	Danielle & John Duddy	Barbara Greenberg	Robert Hunziker	Alyson Lowery
Linda Burks	Matthew & Stephenie	Jacob Greene	Dalton Huston	Philip Lundquist
Kevin Burleigh	Duddy	Kasey Greene	Alex Jenkins	Franny Mardigian
Gerald Burroni	James & Tracy Duddy	Bonnie Grossman	Carroll Jenkins	Dr. and Mrs. Rick Marias
The Burseburger Family	& Family	Helen Grossman	Steven Jenkins	and Family
Anne Byrne	Terrence & Christine	Larry Grossman	R. C. Jennings	Larissa Marocco
Sean Campise	Duddy & Family	Paul Grossman	Barbara Jensen	David Martin
Anita Cass	Tess Dunn	Sonya Haggett	Grace Jensen	Gary Masching
Lauren Catron	Maxine Eggerth	Alex Hampton	Ed Jensen	Jean Mathews
Carol Christensen	Andrea Eisenman	Liz Hampton	Lindsey Nicole Jensen	Ron Mathews
Virginia Clapham	Elyse Elconin Goldberg	The Hampton Family	Lisa Jensen	

(Continued on Page 5)



Baby Jason Webster and Family



The Webster Family.

Clare and Justin Webster have a new baby boy!
Clare (an adult with CF, post double-lung transplant)
has been on staff with CFRI for over a year.

We welcome

Jason Paul Webster
to our CFRI community.



Keeping up to Date: 2007 CF Presentations available on DVD and CD.

Thanks to CFRI volunteer Scott Wakefield, DVD's (\$3) and CD's (\$1) are available for the CFRI General Membership meeting May 2007, and the Stanford CF Education Day, June 2007.

If you would like to place an order, call our office at 650-404-9975.

- *Update on CF Adult Care at UCSF*, Mary Ellen Kleinhenz, MD
- *Moving and Shaking with CF*, John Mark, MD, and Julie Desch, MD
- *From Tragedy to Tranquility*, Paul Mohabir, MD
- *The ABC's of Vitamins*, Julie Matel, MS, RD, and
Plop, Plop, Fizz, Fizz, Oh What A Relief It Is:
NAC Update, Carol Conrad, MD
- *Outcome Measures and Vision*, Carlos Milla, MD
- *The Research Pipeline: The Spigot Opens*, Richard Moss, MD
- *Lung Transplantation for CF*, David Weill, MD
- *Sinus Update and CF*, Peter Hwang, MD

In Honor of (Continued from Page 4)

Nahara Mau	Rose Marie Nuccitelli	Margaret Regan	Janice Shaul	Hope Uskoski
Corey McAlister	Ben Oneto	Melissa Reta	Rachel Silver	Betty Viering
Claire McCabe	Alymaris O'Reilly	Michael Reuscher	Joe Sinnaeve	Betty Vitousek
Rachel McMullen	Killian O'Reilly	Mr. and Mrs. Brian Reynolds	Al Sola	Mat Vitousek
Rebecca McMullen	Maddie O'Reilly	Rebecca Roanhaus	Matt Spadia	Robert Victor Vogel
Carly Lee McReynolds	Michael Eli Orlen	Erin Roberts	Ethan Spain	William Vogt
Nancy Michelle Melvin	Scott D. Parks	Jake Roberts	Megan Stacy	Devin Wakefield
Cassie Merrill	William Pelzl	Ben Robertson	The Stacy Family	Martha Wakefield
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Alex Moore	John Plett	Rob Robinson	Norma Stuckert	Ricky Whicker
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Maryann Mullen	Terri L. Price	Colleen Rue	Mr. and Mrs. Tim Talbot	Lauren Williams
Eilene Neidrauer	Allison Primack	Lauren Russell	and Family	Nina Wine
The Charles Nelson	Jeanne Primack	Katelyn Salmont	Heidi Tegner	Denise Wold
Family	Robyn Primack	Corey Sarkis	The Thibault Family	Emily Woods
Jessica Nett	Todd Primack	Jean Sarkis	Adam Thompson	
Alison Neumann	Dr. and Mrs. Daren	Peter Sarkis	Todd Trisch	
Debbie Neumann	Primack and Family	Eli Scagnelli	Rosemary Turk	<i>* Sadly, Ryan Coelbo</i>
Liesl Neumann	Justin Raines	Justin Schoonmaker	Robert Turk Bly	<i>and Jennifer Uskoski</i>
Pete Neumann	Robert Rasmussen	Brady Scilingo	Jeff Uskoski	<i>passed away prior to</i>
Maureen Nuccitelli	Briauna Red	Myranda Selvage	Jennifer Uskoski*	<i>this printing.</i>

In Memory of

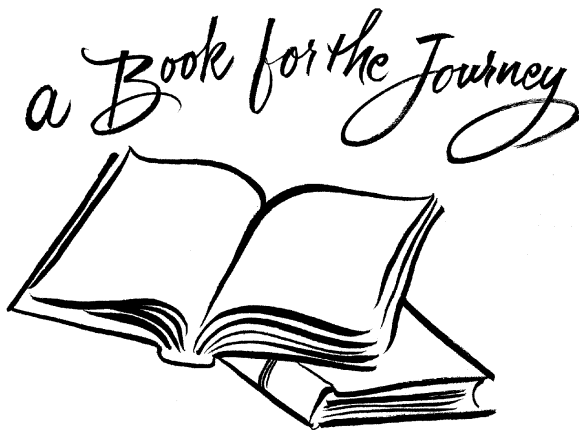
(From October 1, 2006 to May 31, 2007)



“In Memory of” is a donation made in the name of a deceased person. The “In Memory of” is not only for those with CF but for their families and relatives as well. We extend our deepest sympathy to their families and friends. These gifts continue to give hope to children and adults with cystic fibrosis. **Note: Occasionally a deceased person will have the same name as a living person.** Send name of the deceased, the name and address, city/state, zip of the relative/spouse, etc. that you would like acknowledged a donation was made. Send to: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043.

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Fern Adelman	Dennis Cooper	Tina Groleau	Jennai Kodis	Michael Moore
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“Parenting Children with Health Issues”

By Foster Cline, M.D. and Lisa Greene

When I was asked to write about this book, I first asked, why me? I’m not a writer. I am just a grandmom to a child with a health issue – Cystic Fibrosis. I didn’t feel I could give it full justice for what it means to me. It is a very powerful book that not only provides all the in’s and out’s, nooks and crannies, why’s and why not’s, what and what if’s to folks in this position. It dots all the i’s and crosses all the r’s.

There are many thoughts, concerns, needs and challenges for these families – I know! I have heard them and even had some myself. People used to refer to Dr. Spock’s books as the

first-aid book for babies. Well, “Parenting Children with Health Issues” far exceeds that, and it simply does it all! I said before, after critiquing it in its development stage, it’s better than anything I’ve ever read for parenting and special children. We need this.

Having worked as a teacher 20+ years and then working with many families in the Cystic Fibrosis Community and having five children and ten grandchildren, I would say I have been “exposed” to many families that this book will provide insight to and help them daily.

I feel this book goes much further than just helping families. It will become a tool of choice for many professionals who work with these families to help guide them to a much happier and healthier life.

I agree with Dr. Frazier King when he said “a few books fall into the Great Work category. This is one of them.”

Thank you Dr. Cline and Lisa Greene and all the folks who helped Love and Logic give us “Parenting Children with Health Issues.”

Reviewed by Beverley Donelson, CF Pharmacy Florida

In Memory of (Continued from Page 6)

Judy Rockhold
Pamela Rockhold
Donald Rorher
Lillian Roslan
John Ross Moran
Katherine Rossi
William “Bill” Ruffner
John Runge
Sophia Sachs
Caroline Saly
Michelle Sanderson
Grandma Saxton
Maureen Sazio
Dhea Schalles
Linda J. Scherschel
Edith Schlotterbeck
Elaine Schneider

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Elizabeth Templeton
The Thibault Children
Patricia Thibault
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John Trask
Louis Anthony Trigueiro
Holly Tringl
Phyllis Tripp
James Tyrrell

Alta Velasquez
Jodi Lynn Voller
Kenneth Wastell
Nicky Wastell
Viola Wastell
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Adam West
Hayley C. Wester
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Kelly A. Wilson
Lena Woods
Bertha Zashkoff

Cystic Fibrosis Research, Inc.

Our Mission

Cystic Fibrosis Research, Inc. exists to fund research, to provide educational and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease.

Our Vision

As we work to find a cure for cystic fibrosis, CFRI envisions informing, engaging and empowering the CF community to help all who have this challenging disease attain the highest possible quality of life.

Get to know us: www.cfri.org • 650.404.9975

CFRI: a 501(c) (3) non-profit organization, Federal ID# 51-0169988

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2672 Bayshore Parkway, Suite 520
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