

CFRI NEWS

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An Educational Community Contribution by CFRI

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Studying the Antibacterial Activity of Protegrin

Neal Schiller, Ph. D., Professor of Biomedical Sciences and Interim Dean, Graduate Division, University of California at Riverside

Dr. Neal Schiller is investigating the action of protegrin PG-1, a cationic antimicrobial peptide, against *Pseudomonas aeruginosa* and *Burkholderia cepacia*. PG-1 is similar to the type of peptide produced by our body's normal defenses, has broad antibacterial activity against pathogens, and is thought to cause rapid killing activity by changing the permeability of the pathogen's outer membrane. These peptides are small in size, easy to produce and modify, and bacterial resistance to their action is difficult to induce in the lab. The study has found that the protegrin PG-1 is effective against *P. aeruginosa*, and has the potential to be developed into an effective antibacterial treatment. However, presumably due to structural differences in the bacterial membranes of *B. cepacia*, protegrin PG-1 binds less effectively to these strains and is unable to kill these bacteria. Studies in progress will characterize which structural differences in *B. cepacia* are responsible for blocking the action of the agent, and whether other cationic peptides might be effective against these bacteria. ■

RESEARCH
Your CFRI Dollars at Work



Craig Burrell Photography

Neal Schiller Ph.D., comparing notes with Peking Fong, Ph.D., another CFRI-funded researcher.



Craig Burrell Photography

Electron Microscopical Studies Made Possible Through CFRI Grant

Jacob Bastacky, M.D., Associate Research Scientist, Children's Hospital Oakland Research Institute, Oakland, CA

Dr. Jacob Bastacky has made powerful electron microscopes available to local CF researchers thanks to a CFRI research grant. In electron microscope photographs, the investigator can see the "landscape" of the lung lining and is able to observe in great detail the function and interaction of various elements in that landscape. The CFRI grant is currently supporting access to electron microscopes for six projects, and several other studies will soon be supported by this same grant. One project is looking at the structure of the cilia on the lung surface. Another is assessing the composition of the liquid on the surface of the airways. A third is looking at developing new ways to cultivate CF tissues for use in research. Still another is examining transplantable lungs in an effort to come up with new methods for storing the lungs for longer periods of time. ■

Jacob Bastacky M.D., with his daughter, Leah.

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Letter from the Executive Director

CFRI'S New Beginning

By Calvinia Williams

As we all wait in anticipation for further developments in CF research, CFRI starts the year off with a new location and the challenges that accompany a major move. We apologize if you had trouble reaching us during our transition. We were assured before the move that all would go smoothly, but our email and phone service did suffer several periods of disruption. We hope you were not greatly affected and trust that our technology problems are resolved. We sincerely appreciate your commitment to CFRI. It is because of you that we continue to strive for excellence.



Calvinia Williams, Executive

Craig Burleigh Photography

CFRI is constantly growing and changing as we endeavor to become a better resource for all of you. Many of you may remember CFRI's Cackler Newsletter. It was a small newsletter, aimed at youngsters with CF who had attended camp but could no longer participate due to new and stricter cross-infection guidelines. This was a short-term effort until camp could be made risk-free for the kids. This has not proved possible, so CFRI plans to re-invent this old newsletter with a new face for a larger audience. It will be written for and by our youth, giving our 8-15 year-old children a voice in our community and connection to each other. Please see page 4 for details.

Our CFRI staff, in conjunction with our volunteer committees, is currently preparing for a variety of events. Our biggest fundraiser, the Mother's Day Tea, will be kicking off by the time you read this newsletter. We are hard at work on the 2001 Conference, planned for August 10-12, 2001. The CFRI Golf Committee and the Mackey family are both hard at work on their respective Golf Tourneys. And the CF Teen/Adult Retreat, August 6-10, 2001, is in the late planning stages. Please be sure to mark your calendars for these wonderful events (details for all of these events are enclosed).

Your support and hard work have made CFRI's success possible. Once again, the time has come for us to ask for your help. We urge you, your family and your friends to participate in our Mother's Day Tea by writing tea letters and by contributing to this fundraiser. We need your help if we are to continue to put on first-rate educational events for our families. Please volunteer and make this our most successful Tea ever! Many people have already participated in the 2001 Tea. Let me start by thanking Biglow Tea, Inc., which has once again donated over 16,000 tea bags for this year's campaign. We acknowledge Biglow for their years of support for CFRI and the difference they have made in the lives of our CF families. Secondly, Digestive Care, Inc. covered the costs of the typesetting and printing of our Mother's Day Tea informational insert featuring Sebastian Fabricius and his beautiful family. Dawn Fabricius provided priceless photos to help create this intimate but educational brochure. We are grateful to Walgreen's Cystic Fibrosis Specialty Pharmacy for sponsoring the printing costs of the Tea Invitation. And special thanks go to Kristen Parodi, mom of Gabriel and aunt of Kaitlyn, who photographed these two precious children for the cover of our Tea Invitation. These companies and families are to be commended for their efforts and major contributions to CFRI. The Tea is a community event just waiting for your participation.

We are encouraged that a new beginning for CFRI will open more doors for research, support and education. We welcome your thoughts and ideas. Please feel free to drop me a line at cfri@cfri.org. Your opinion is very important. We also welcome visitors to our new CFRI offices. We would love for you to see our new space.

Never doubt that your contribution can make a difference in the life of someone with CF. In fact, it's because of your efforts that we have come so far.

Calvinia Williams,
Executive Director, CFRI

GOOD NEWS

For People with CF and their Families

Ann Robinson successfully undergoes Hip Replacement Surgery

Ann Robinson, former Executive Director of CFRI, underwent hip replacement surgery on February 14, 2001 at Stanford University Hospital. She spent three days in the hospital before being transferred to Sharon Heights Convalescent Home in Menlo Park, CA for a one week respite. Ann had been in chronic pain in several of her joints due to osteoarthritis. She was very eager to have the surgery in hopes that it would enable her to resume her normal activities. Depending on the success of this surgery and how she recuperates, doctors may replace the other hip in the future. Her husband Rob has been busy preparing the house for Ann's return home. Ann is currently recuperating at home and doing very well. CFRI and all of its members wish Ann a very speedy recovery. Our prayers are with you. Get well cards sent to the CFRI office will be forwarded to Ann's home address.

Parenting Classes Offered at Packard Children's Hospital at Stanford for Parents of CF Children

Packard Children's Hospital at Stanford is offering an ongoing course for parents addressing the challenges of parenting a child with cystic fibrosis. The curriculum was written by social workers, people with CF and parents of chronically ill children. A group of parents signs up for a series of seven classes that meet for two and one-half hours one evening per week. The classes are being sponsored by Patient and Family Support Services at Lucile Salter Packard Children's Hospital at Stanford, and thanks to a grant from Genentech, Inc. and Chiron Corporation (formerly PathoGenesis), admission is free and child care is provided.

Class discussions include communication within the family, adherence to medication schedules and treatments, managing stress and future uncertainties, discipline, school-age issues, socialization, peer relationships, the parents' marital relationship, finding meaning and hope, managing the disease, and improving communication with doctors and other health care providers.

After taking the final class, prior attendees wrote what was most helpful for them:

- Sharing our thoughts and feelings so we know we are not alone
- Being reminded of good health practices
- Learning techniques for dealing with problems
- An outlet to share with others
- Valuable curriculum...making friends
- Great ideas for successfully managing problems with CF and invaluable personal experience with CF.

If you would like additional information about these classes, please contact Isabel Stenzel-Byrnes at 650-724-3314 or Ann Robinson at arobinson@goldenworld.com. ■



Craig Burrell Photography

Ann Robinson at a recent CFRI event.

CFRI to Put out a Newsletter for Kids with CF!

The CFRI Youth Newsletter will appear for the first (and possibly second) issue as a pull out in *CFRI News*. Next year it will be sent out separately three times per year (for starters) for any parents and children requesting a subscription. This newsletter is intended to reach the children that used to be eligible for CF camp who need a safe way to connect with other children with CF. It is also for their siblings and close friends. We intend for the newsletter to be upbeat, written primarily by and for the children, occasionally educational, and include poems, jokes, artwork and photos. We are soliciting submissions from your children on any subject, their accomplishments, their strategies for taking meds or doing treatments, their feelings about living with cystic fibrosis or any other childhood events, joys or stresses.



Katie Weber, age 13, Volunteer Youth Editor for the CF Children's Newsletter.

Katie Weber is the 13-year-old daughter of Carol Tusin-Weber, an active CFRI member, a CFRI Liaison to her community, and mother of three. Katie's younger brother (aged 10) and sister (aged 7) both have cystic fibrosis, so she is well acquainted with

the disease. Katie, currently an eighth grader at 29 Palms Junior High School, near Palm Springs, CA., will become the Volunteer Youth Editor of our new newsletter for children with CF ages 8-15. Kathleen Flynn, CFRI's Outreach Specialist, will be her office support and editorial mentor on the project. Katie is interested in art and calls herself an average student. Career options that she is considering include animal rescue and rehabilitation, or the scientific study and breeding projects of endangered species. She is thrilled to be our Youth Editor.

Katie will start the newsletter off with a **Contest for a Name**. She asks children to email their ideas for a name for the newsletter to her along with a reason why they picked that name. Also send in your stories, poems, letters and short articles. Send submissions, name ideas or requests for subscriptions by email to Katie Weber at cfriteeditor@aol.com or send it by regular mail to the CFRI office c/o Kathleen Flynn, CFRI, 2672 Bayshore Pkwy., Suite. 520, Mountain View, CA, 94043.

Treat Yourself To The CF Teen and Adult Retreat

By Isa Stenzel-Byrnes

You are all invited to attend the Annual CFRI Teen and Adult Retreat **Monday, August 6 through Friday, August 10, 2001** at the Vallombrosa Retreat Center in Menlo Park, CA. The retreat provides a safe and comfortable environment for people with cystic fibrosis, age 16 and older, to share their unique experiences, coping strategies and feelings about living with cystic fibrosis. Here are some comments about last year's retreat:

- "I briefly attended a few evenings and was deeply affected...I was particularly emotionally vulnerable and found the support at retreat invaluable at this time in my life."- 28 year old with CF
- "I found the retreat site extremely peaceful. In addition, the food was fantastic. This year I gained 4 pounds! ... The whole staff made sure we were safe..." 35 year old with CF
- "Spending time with other teens that had CF was so awesome. When we first met each other we immediately had an incredible bond that no one could break and that will last forever.... We listen, and right away understand what each other is going through."- 16 year old with CF.
- "Going to retreat now, and camp as a child, was the single, biggest influence on my life outside of my family. Go to retreat! I would much rather have CF and know the love of retreat than never know the love and be healthy..." -20 year old with CF

The retreat focus is on caring for oneself, physically, emotionally and socially. Activities are aimed at enhancing positive coping skills for surviving and thriving with cystic fibrosis. The recreational activities include daily physical exercise, arts and crafts, a talent show and dance. Educational activities include workshops on nutrition, college and career planning, and an informal "Question-and-Answer Session with an Adult CF Physician". Older adults serve as invaluable role models for younger people with CF, yet they also have time to forge their own sustaining relationships with other adults. Retreat dates are planned so that people coming from out of town can also attend the CFRI Educational Conference the following weekend.

A medical advisor is available at the retreat to monitor the health of all participants and ensure that cross-infection protocol is followed. Only 40 overnight spaces are available. Registration is on a first-come, first-serve basis. If you are unable to attend, join our retreat community via cyberspace at www.javaboard.com/cfboard. The retreat committee also hosts a Holiday Party in Palo Alto, California, each December. We would love to see former campers and prior attendees return to CF Retreat, and we welcome all newcomers! For more information contact CFRI at cfri@cfri.org to request an application packet, or call CFRI's Program Manager, David Soohoo at 650-404-9975. ■

Attendees from the 2000 Retreat at Vallombrosa.



Craig Burleigh Photography

Results of Internet Support Group for Teens with Cystic Fibrosis

By Kathleen Flynn

Because it is difficult for people with CF to gather together, they must identify other means of support. Internet chat rooms and CF e-mail support group lists (like Cystic-L and ConColl) benefit many of us, however, we discover them almost by accident. It is not in the usual repertoire of support services recommended by our medical professionals...but this may change.

According to an article that recently appeared in *Pediatrics*, Dr. Kevin Johnson and his colleagues at Johns Hopkins University School of Medicine in Baltimore, Maryland recently created a web-based support service for adolescents with cystic fibrosis (CF). They wanted to measure, both qualitatively and quantitatively, the effects that such a support site could have on patients' relationships with the clinic faculty and staff, access to and interaction with peers with CF, and understanding of CF. They developed a highly interactive electronic support group after discussions with a team of CF specialists and patients. Eighteen of 37 teenagers with CF agreed to use this site. Each patient was asked to assess his or her perceived availability of and comfort with the clinic staff and faculty, perceived support available through peers, knowledge about CF, and perceived usefulness of the Internet as a support tool.

Ultimately, participants logged into the site an average of four times each month. Not surprisingly (at least to parents of teens), most activity occurred in those sections of the site that described the participants and that allowed them to socialize. Over one-half of the participants e-mailed each other at least once a week, with 77% e-mailing peers at least every other week. And although there was no significant difference in the participants' scores on a quiz about CF at the beginning and the end of the study, there was a significant decrease in what the teens *perceived* that they knew.

More importantly, while many of the perceptions initially measured did not change significantly when assessed after the study, participants did believe that they had more friends whom they could relate to than they did at the beginning of the study. Clinic staff noticed an increase in references to peers among the group who were using the site. In addition, four of the teens expressed a desire to get together to meet each other as a result of their interactions on the web site. Doctors concluded that the social and expressive aspects of their involvement with this support group hold much promise. For more information about support for your teen, see the article on the CFRI sponsored Retreat on page 4. ■

CFRI Welcomes David Soohoo, CFRI's New Program Services Manager

David Soohoo was born and raised in the Chinatown district of San Francisco. He received his formal education through the San Francisco Unified School District and graduated with a Bachelor's degree from San Francisco State University. He began his working career as an accountant and transitioned into marketing, merchandising, sales promotion and sales, spending the last 30 years in numerous corporate environments. The last four years were spent as a consultant to a retail co-operative.

David is married to Marcella and they have two children, Karen and Jonathan, both teenagers. He and his family have resided in Menlo Park for the past 20 years.

David believes in being involved with local community issues and having a pulse on global concerns. In accepting the position at CFRI, he hopes to assist our efforts in supporting and educating people with cystic fibrosis while we seek an end to this devastating disease. David begins his role by supporting the Retreat Committee in their efforts to put on this year's retreat. He is also primarily responsible for the office support of the Research Advisory Committee. Eventually, he will also take an active role in coordinating the Annual Educational Conference.

Please stop by the office and welcome David to our community. He would love to get to know all of you. We are very lucky to have his energy and intelligence at CFRI. ■

Don't Throw Out Leftover Medications or Old Medical Equipment!

The Flying Doctors (Los Medicos Voladores) is a group of volunteer medical professionals dedicated to providing care for underprivileged children and adults in poor countries. Fred and Roberta Roads of Livermore, CA are dedicated to collecting medicines and medical equipment that people or hospitals would otherwise throw away. They package up these much-needed supplies and send them to 53 hospitals and clinics in Mexico. If you have unopened medicines that you won't be using or medical equipment that you no longer need, please don't dispose of them. The Roads will even accept expired medications so long as they are not older than six months past the expiration deadline.

Fred and Roberta Roads will also arrange for a pick up in your area. To date, they have traveled as far south as Gilroy, as far north as Calistoga and Santa Rosa, as far west as Half Moon Bay and as far east as Sacramento for pick ups. Small packages of medicines can be mailed to them. You can reach Fred or Roberta Roads at 925-447-7394.



David Soohoo in his new office.

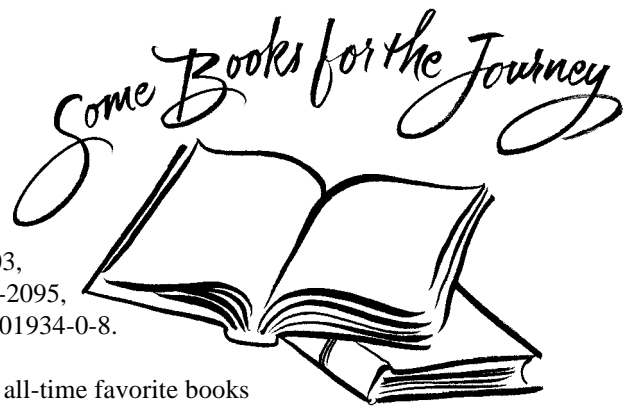
Pharmaceutical News

Solvay Pharmaceuticals, Inc., of Marietta, Georgia, a maker of the Creon® pancreatic enzymes, has awarded Dr. Shea Ross of the University of Florida College of Medicine a five-year fellowship grant. The grant will assist Dr. Ross in evaluating pancreatic enzyme deficiency after pancreatic surgery, and in investigating synthetic forms of secretin, a gastrointestinal hormone used in diagnostic testing for chronic pancreatitis. Ross was awarded the Solvay Pharmaceuticals/University of Florida Pancreatic Research Fellow Career Award, as part of a \$50,000 yearly grant to the University of Florida division of gastroenterology, hepatology and nutrition. The grant will help support pancreatic research fellowships at UF.

Each year Solvay Pharmaceuticals awards college scholarships to students based on academic achievement, leadership qualities, financial need, and ability to serve as a role model to others who have CF. All high school seniors, vocational school and college students who have CF are eligible. Students receive \$2,000 per year for up to four years or until completion of their current degree. Applications are usually available at CF treatment centers each year from March 1 through June 29. Contact your local CF Center for more information.

By Kathleen Flynn

The Spirit of Lo: An Ordinary Family's Extraordinary Journey, by Terry and Don Detrich © 2000, Mind Matters, Inc., P.O. Box 52503, Tulsa, Ok 74152-0503, 1-877-222-2095, www.SpiritofLo.com ISBN: 0-9701934-0-8.



Without a doubt, this is one of my all-time favorite books on the subject of cystic fibrosis. Written from the parents' perspective with alternating chapters by Terry and Don Detrich, it gives a primarily chronological account of how their daughter's cystic fibrosis affects the Detrich family, their marriage, their daughters and themselves.

As I read the book, I found myself wishing that the Detrichs had called this book *The Detrich Spirit* or *The Spirit to Fight Cystic Fibrosis*. Their daughter Lauren, nicknamed Lo and hence the title, is, without a doubt, a highly remarkable person. And the story does describe Lo's incredibly resilient spirit, her personal battle with CF (physical, emotional and spiritual), her delightful personality, and her inspirational drive to help raise money for CF research. However, from my reading, I was touched by the whole family: the parents of the two children, the second of whom was diagnosed with CF at the age of three months, and how CF affects all of their lives. Indeed, these authors call upon all of their wisdom, inner strength of character, outer resources, humor, and love for each other and their children to be able to both accept CF, and to fight like demons to keep it at bay. The Detrichs are role models for all of us, and yet they don't pretend to be perfect. They worry about their mistakes and describe their struggles, even those that they may never overcome. Their determination was particularly inspiring.

While the Detrichs work hard for many of their resources, they also have a lot going for them before they ever face CF. They have a comfortable home, a solid marriage, deep and abiding faith (which is tested by CF), financial stability, insurance (albeit with a lifetime cap fast approaching!), good friends, and phenomenal endurance. They also have access to first-rate CF medical care, (which on at least one occasion was facilitated by their excellent relationship with the CF Foundation). However, even if your talents and situation are less fortunate, reading this book may turn out to be one of the most normalizing experiences a parent or relative facing CF could have. The Detrich's feelings and experiences are universal in the daily family fight with CF. Feelings of parental love, grief, desperation, joy, anger, longing, devotion, worry, pride, loss and exhaustion are all there on every page. I encourage any parent raising a CF child (of any age) to read this book. Any relative or family friend wondering what it's like to live with CF will be astonished. CF teens and adults looking for a non-threatening understanding of what it is like to parent a CF child will also appreciate this book. And it would be a wonderful asset to any parent or CF support group, opening up tough discussions that are so critical to the realization that we are not alone with our struggles with CF. I am grateful for the gentle immersion into the lives of this family. It provided a comfort and normalcy to my own life that I hadn't felt recently. With any luck, one day Lo and Jane will each write a book from the CF teen and sibling perspective with the same refreshing honesty as their parents. I'll be the first in line to read them!

Cystic Fibrosis Medical Care, by David M. Orenstein, Beryl J. Rosenstein, and Robert C. Stern, © 2000 Lippincott Williams & Wilkins, ISBN: 0-7817-1798-1.

This is an excellent short paperback text and general reference book written by several leading CF physicians in the U.S. It is aimed at CF professionals and other medical care providers who work with CF patients. It describes the molecular and cellular bases of

(Continued on page 15)

Meet the New Members of CFRI's Board of Directors

Meet CFRI's newest members of the CFRI Board of Directors: Patricia (Pat) Flynn, Sonya Haggett, Scott Hoyt, and Ana Stenzel. The first three were voted into office at our October 2000 Board Meeting and will serve a year-long term. Ana Stenzel was elected by the Board to replace her sister, Isa Stenzel-Byrnes who stepped down in January.

Pat Flynn

Pat Flynn has been an active member and volunteer for CFRI for ten years and is serving on the board for the second time. She has worked on fundraisers through the years such as the CFRI golf tournament auction, the Ride and Stride bike/walk-a-thon, and the Mother's Day Tea. She is currently assisting with the CF Teen/Adult Retreat. For the last few years Pat has managed the note cards and tags fundraising project. She is always developing new and novel items for sale at crafts fairs. She is married to Michael Flynn, has four grown children, one of whom is Kathleen Flynn, CFRI's Outreach Specialist, and seven grandchildren, including Devin, Kathleen's nine-year-old son who has CF.



Pat Flynn

Sonya Haggett

Sonya, an adult with CF, is returning to the CFRI board of directors after a short leave. This year marks her third year as a board member. Her main participation in CFRI has revolved around the Teen/Adult Retreat, and she will continue to be involved in the Retreat this year. Outside of CFRI, she is a sales rep for a corporate Internet service provider. Her hobbies include yoga, salsa dancing and cooking. Sonya lives in Oakland, California. Welcome back, Sonya!



Sonya Haggett



Scott Hoyt

Scott Hoyt can often be seen on a golf course and that's because he not only has a passion for golf, but also because it is his job! Scott is the General Manager of the Cinnabar Hills Golf Club in San Jose. He will chair the annual CFRI Golf Tournament for the second time. He is married to Anne and has two children, Erinn, age 10, who has CF, and Kristen, age 8. His special interests are, in his words, "my wife and family and whatever my children are interested in."

Scott Hoyt

Anabel Stenzel (from Isa to Ana)

Ana Stenzel replaces her twin sister, Isa, on the Board of Directors. Ana is a long-time member of CFRI, having served on the Retreat committee for many years. She and Isa are 28 years old and both have CF. When Isa resigned due to numerous other time commitments, she recommended her twin sister, Ana as a replacement. Ana, who had been unable to help in recent years due to a health decline, received a double lung transplant last summer. She is now in good health and has the energy to take on this challenging position.

You may remember Ana as the maker of the beautiful Roses Hope Necklaces available for sale at the Conference.

In instances where a Board member steps down, the CFRI By-laws require the Directors to appoint a new board member to the vacated position until the annual vote for the slate of Directors in October. Welcome Ana!



Anabel Stenzel

Sequencing the *Pseudomonas aeruginosa* Genes

Researchers at the University of Washington and the Seattle-based biotechnology company PathoGenesis Corporation (which is now a subsidiary of Chiron Corp. in Emeryville, CA.) announced in August, 2000, that they have sequenced the 5,500 genes of *Pseudomonas aeruginosa*, the largest bacterium yet to be mapped. This is significant news for people with cystic fibrosis, burn victims, and AIDS and cancer patients. *Pseudomonas aeruginosa*, a common cause of serious lung infections in people with cystic fibrosis, is particularly resistant to known antibiotics. By sequencing all the genes in the bacterium, scientists are now closer to understanding how such an adaptable bacterium lives in different environments and is able to resist antibiotics. With this knowledge they now can develop new drugs to destroy this common bacterium. ■

Digestive Care, Inc. Offers Assistance Program

Digestive Care, Inc., makers of Pacrecarb® (pancrelipase) enzymes, offers The Assistance Program to indigent patients who are not covered by medical insurance, Medicaid or other third-party payers. Eligibility is determined on a case-by-case basis.

To participate in the program, your physician must submit a written request outlining the situation and indicating what kind of assistance you need. Once approved, medication labeled for the specific patient will be sent at no charge directly to the requesting physician. Normally, a three-month supply will be shipped per each approved request. Requests will be processed as soon as they are received and medication will be shipped within five working days. Your physician must send a follow-up letter to request each subsequent shipment. Send requests to Digestive Care, Inc., The Assistance Program, 1120 Win Drive, Bethlehem, PA 18017-7059. ■

Behind the Scenes at CFRI: Meet Two New Research Advisory Committee (RAC) Members

Editor's Note: In a recent issue of CFRI News, we featured members of the Research Advisory Committee. Below we welcome two additional RAC members.

Liz Nash is a 30-year-old CF adult who has a Ph.D. in Human Genetics. In her own words, "I moved to the Bay area about a year ago and recently attended my first CFRI retreat and second conference. I have been very impressed with the educational programs CFRI provides and the supportive community it has created. I wanted to be involved in CFRI programs and thought that I could best contribute by serving on the RAC. I participated in CF research in the lab of Garry Cutting, M.D., at Johns Hopkins Hospital as an undergraduate and more recently in the lab of Bill Welch, Ph.D., and Marybeth Howard, Ph.D., at UCSF. I am happy to serve on the RAC to contribute whatever I can from my educational and research experience and to keep pace with the advances in CF research. I enjoy working with the RAC members who spend a great deal of time evaluating proposals. It is a thrill to read cutting edge research proposals from scientists working extremely hard to better understand the causes of CF and discover ways to clinically manage and treat the disease."



Liz Nash, Ph.D., our newest addition to CFRI's Research Advisory Committee



Scott Pinner at an earlier CFRI Retreat.

Scott Pinner is a 25-year-old adult with CF who has served on the Board of Directors for three years and a year ago joined the RAC. In his own words, "I am currently in my third year of medical school at UC Davis with the goal of becoming a pediatrician. I was diagnosed with CF at the age of three and told I would be dead by the age of 6. My mother called every conceivable source to get more information on the disease. One of the organizations she contacted was CFRI. They gave her information about the disease and its cause. I have attended CF retreats since I was five, with CFRI sponsoring the later ones. I felt a need to give back to the organization that gave so much to me. I enjoy working on RAC because it allows me to use my medical and research backgrounds and personal experience to influence funding that I think is critical to the progress of understanding the disease and finding a cure." ■

Thanks to the Following Sponsors for their Generous Support of the Mother's Day Tea!

- **Bigelow Tea** for donating 16,000 Herbal tea bags!
- **Digestive Care**, makers of Pacrecarb® (pancrelipase) delayed-release enzymes (610-882-5950 or digestivecare@fast.net), for underwriting the costs of typesetting and printing the Mother's Day Tea informational brochure.
- **Walgreen's Cystic Fibrosis Specialty Pharmacy Program** for patients with CF and their caregivers (1-888-782-8443), for underwriting printing and production costs of the Tea Invitation.

The generosity of these companies greatly enhances our ability to support cystic fibrosis research and to provide educational programs and materials to patients and their families. ■

Plan Ahead for CFRI's Annual Educational Conference!

This year's conference will take place at the DoubleTree Hotel in San Jose, California on August 10-12. Save the date and start making plans to attend. Look for fliers to arrive in early June. Our fabulous line-up for the 2001 conference includes the following renowned speakers:

- Tomas Ganz, M.D., Ph.D., Research Scientist from the University of California at Los Angeles, will give an update on basic research;
- Frank Accurso, M.D., CF Center Director from Denver Children's Hospital, will give an update on clinical research practices;
- Dana Hardin, M.D., pediatric endocrinologist from the University of Utah, will speak on nutritional issues affecting Cystic Fibrosis Related Diabetes, (CFRD), and osteopena in CF;
- Myra Bluebond-Langnor, Ph.D., Distinguished professor of anthropology and Director of the Center for Childhood and Child Studies at Yale University, also author of *In the Shadow of Illness*, will speak on coping with cystic fibrosis in the family;
- Daina Kalnins, R.D., nutritionist from Toronto's Sick Children's Hospital, will speak on the esteemed nutritional protocol practiced at their center and address the topic of essential fatty acids and CF.
- Dr. Walter Robinson, from the pulmonary division of The Children's Hospital in Boston, will speak on end-of-life issues in CF. ■

Vote for the CFRI Professional and Volunteer of the Year Award

Do you know a first-rate CF professional who goes above and beyond the call of duty? Are you aware of someone in the CF community who volunteers their time endlessly in support of people with CF? Nominate your favorite professional and/or volunteer for the 2001 CFRI Volunteer of the Year and the 2001 CFRI Professional of the Year Awards, presented annually at the CFRI Conference. E-mail your nominations to cfri@cfri.org, send them to CFRI, Attention Kathleen Flynn, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043, or fax them to CFRI at 650-404-9981. ■

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Save the Date!!

Dr. Neils Hoiby to Speak at CFRI General Meeting On His Studies into Prophylactic I.V. Antibiotic Therapy

Dr. Neils Hoiby, M.D., D.M.Sc., and Professor in the Department of Clinical Microbiology at the National University Hospital, Righospitalet, in Copenhagen, Denmark will speak at CFRI's spring General Meeting. The talk will take place at the Lucile Salter Packard Children's Hospital at Stanford Auditorium in Palo Alto, California, on Sunday evening at 7 p.m., May 20th (this is the only evening Dr. Hoiby is available). Dr. Hoiby spoke at the 1995 CFRI/IACFA joint educational conference in Palo Alto, California. He gave an excellent presentation on his approach to treating cystic fibrosis in Denmark, which emphasized earlier and more aggressive I.V. antibiotic treatment for bacterial infections such as *Staphylococcus aureus*, *Haemophilus influenzae*, *Burkholderia cepacia*, and especially *Pseudomonas aeruginosa*. Dr. Hoiby is in town for the National Thoracic Society Convention, which will be held during the week in San Francisco. We greatly appreciate that Dr. Hoiby will take time from his busy schedule to visit with people with CF and their families to give an update on his treatment protocol.

Pathogenesis Releases Results of TOBI® Studies

Pathogenesis Corporation, recently acquired by **Chiron Corporation**, headquartered in Emeryville, California, presented data at the 2000 North American Cystic Fibrosis Conference (NACFC) held last November that reinforces the benefits of early treatment with Tobramycin Solution for Inhalation (TOBI®).

The first abstract concluded that patients infected with *Pseudomonas aeruginosa* and treated with placebo in three major CF studies experienced a higher loss of lung function than those who were treated with prednisone, ibuprofen or TOBI for their *P. aeruginosa* lung infections. The abstract is titled *Rates of Lung Function Decline for Pseudomonas aeruginosa-Infected Placebo Patients in the Prednisone, Ibuprofen and Tobramycin Solution for Inhalation (TOBI®) Cystic Fibrosis (CF) Trials*.

The second abstract discussed an analysis of patients enrolled in TOBI clinical trials. The data suggested that TOBI can help reduce loss of lung function in *P. aeruginosa*-infected CF patients with mild to moderate lung function impairment. The study is called *Effect of Tobramycin Solution for Inhalation (TOBI®) on Long-Term Rates of Lung Function Decline in Pseudomonas aeruginosa-Infected Cystic Fibrosis (CF) Patients with Mild to Moderate Lung Disease*.

Additionally, Chiron Corp. has begun a Phase I study of TOBI administered with a proprietary inhaler developed by AeroGen, a privately held company. The AeroGen hand-held, battery powered inhaler could significantly shorten treatment time. Up to 48 patients with cystic fibrosis, age 12 or older, will take part in the study at up to 11 clinical study sites within the U.S. The study will compare the AeroGen inhaler with a jet nebulizer in terms of aerosolization time, ability to effectively deliver TOBI as measured by drug levels in the body, and various safety parameters. The AeroGen inhaler is designed as a convenient and efficient alternative for delivering TOBI. ■

Dos and Don'ts for Dealing with Someone Who Has a Disease

Editor's Note: Someone who discovered these words of wisdom on the Internet sent the following to me. Unfortunately, there was no credit given to an author. If you are the author of the following, write in and I'll be sure to give you proper credit in our next issue. Thanks for your wisdom.

Don'ts

- Don't assume because I look well that I feel well. Looks can be deceiving. Many days I look great but I feel terrible.
- Don't tell me you know how I feel. No one knows how anyone feels. Two people with the same disease may feel totally different. We all have varying thresholds of pain, and pain cannot be measured.
- Don't tell me about your great-aunt Gertrude and her CF, and how well she managed in spite of it. I am not Aunt Gertrude, and I am doing my best.
- Don't tell me, "it could be worse." Yes, it could be, but I don't need to be reminded.
- Don't decide what I am capable of doing. CF doesn't affect the brain. Allow me to decide what activities I can participate in. There may be times I might make the wrong decision, and if I do, I'll know it soon enough.
- Don't be upset that you cannot ease my pain. It won't do any good for both of us to feel miserable.
- Don't ask me how I feel unless you really want to know. You may hear a lot more than you are prepared to listen to.
- Don't assume because I did a certain activity yesterday that I could do it today. Cystic Fibrosis is ever changing.
- Don't tell me about the latest fad "cure". I want to be cured more than anything, and if there is a legitimate cure out there, my doctor will let me know.

Dos

- Do learn everything you can about the disease. The more you know, the better equipped you will be to know what to expect.
- Do realize that I am angry and frustrated at the disease, not with you.
- Do let me know when you are available to help me when I ask. I'll be grateful.
- Do offer me lots of hugs and encouragement.
- Do understand why I cancel plans at the last minute. I never know from one day to the next how I will feel. CF is like that.
- Do continue to invite me to all the activities. Just because I am not able to bike ride along with the gang does not mean that I can't meet you for the picnic at the end of the trail. Please let me decide. Thank you. ■

Aspergillus Infections in People with CF

By Ann Robinson

(Part II in a series of two articles. Part I appeared in the Summer 2000 issue of *CFRI News*)

Our son Carl, who has cystic fibrosis, was first diagnosed with allergic bronchopulmonary aspergillus (ABPA) when he was a teenager. His symptoms included an active lung infection, an IgE blood level of over 2000, as well as asthma, bronchiectasis and *Aspergillus* growing in his sputum. He was given an allergy skin test for *Aspergillus* that indicated he was highly allergic to the fungus currently growing in his own lungs.

The fungus, *Aspergillus fumigatus*, which is the species of *Aspergillus* most frequently associated with ABPA, is frequently found in the airways of patients having cystic fibrosis. Although *Aspergillus* can cause problems, it is different from the infections caused by viruses and bacteria. The problem with *Aspergillus* is not infection with tissue damage, but with the allergic reaction going on in the body that causes intense swelling within the lung airways.

For an estimated 80%-90% of people with CF, *Aspergillus* may be present in their airways and not cause any problems. However, for 10% - 20% of people with CF who are allergic to this fungus, ABPA can present difficult clinical problems.

How is ABPA diagnosed? Diagnosis is made on the basis of both clinical and laboratory tests. The criteria for diagnosis includes: the presence of asthma, pulmonary infiltrates, bronchiectasis, positive immediate skin test, increased IgE levels of greater than 1000, plus other laboratory antibody tests. However, *Aspergillus* should be considered in any patient who is not doing well in spite of maximum therapeutic treatments and who has any of the above symptoms.

It is sometimes difficult to diagnosis ABPA because its symptoms overlap common symptoms of cystic fibrosis. Drs. Peadar Noone and Michael Knowles state in their book, *Cystic Fibrosis in Adults*, "Excluding the ABPA diagnosis is easier than confirming it, and laboratory data alone — without the accompanying clinical syndrome — is insufficient evidence to warrant treatment."

ABPA is controlled by oral and inhaled steroid therapy and sometimes by the use of an oral antifungal antibiotic such as itraconazole (Sporanox®). (When taking Sporanox, it is important to remember that certain medications, such as Prilosec® or Propulsid®, will negate the effectiveness of the drug.) Some physicians also prescribe aerosolized Amphotericin® (an I.V. antibiotic) to combat fungus infections in the airways. To monitor ABPA, physicians look for clinical improvement and lower IgE levels. Many physicians continue therapy for several months, with an emphasis on vigorous removal of secretions from the airways.

In our son's case, it was also important to remove mold from our home, especially in his bedroom. (See Part I of this article in the Summer 2000 *CFRI News*). It also helped him to begin a course of allergy shots that further desensitized him to mold and other allergens that could potentially cause asthma and airway inflammation.

It is very important to treat asthma and ABPA in CF patients because they both can seriously exacerbate CF symptoms. Please consult your physician if you have questions concerning asthma and/or ABPA. Also, CFRI has several interesting articles on ABPA. Please call the CFRI office at 650-404-9975 or email Kathleen Flynn at cfri@cfri.org for more information. ■

Announcing the 17th Annual CFRI Golf Tournament

The CFRI Golf Committee, chaired by CFRI board member Scott Hoyt, invites all golfers to the 17th Annual Golf Tournament on Monday, August 6, 2001 at the Cinnabar Hills Country Club in San Jose, California. Help CFRI raise funds while having a great time! More details can be found on our website www.cfri.org in the coming months.



Research Funded in 2000

Research Advisory Committee

Editor's Note: The CFRI Research Advisory Committee voted to fund only one cycle of funding in future years. Research proposals requesting funding in 2001 must be submitted to the CFRI office no later than July 2nd. The final vote by the Board of Directors and the General Membership on the RAC's recommendation for funding will occur at the end of October, 2001. The total funds awarded in 2000 amounted to \$173,787.00.

Spring Cycle

1. Jeff Wine, Ph.D., Director, Cystic Fibrosis Research Lab, Stanford University, Stanford, CA., Principal Investigator. *CFTR, Glutathione (GSH) and Neutrophil Function*, Rabin Tirouvanziam, Ph.D., Research Scientist.

This study is testing whether cells lacking the CF chloride channel release less glutathione (GSH) into their environment such that microbe-killing mechanism of the neutrophils is impaired. Dr. Tirouvanziam's goal is to provide a model for the small airways which provides understanding on the use of CFTR to transport GSH and support neutrophils during the microbe-killing process.

Amount funded: \$44,287

2. John LiPuma, M.D., University of Michigan Medical Center, Ann Arbor, MI, Principal Investigator. *Prevalence of Sputum Culture Negative Burkholderia Cepacia Colonization in Northern California CF Centers*.

This is a request for an additional six months of funding to study gram negative cultures in Northern California CF centers.

Amount funded: \$23,000.

Fall Cycle

1. Jonathan Widdicome, Ph.D., Children's Hospital Oakland Research Institute, Oakland, CA. Program Director of the CFRI Bay Area Fellowship/Post-Doctoral Training Program in Cystic Fibrosis.

The CFRI Fellowship Training Program continues to expand. Ultimately, annual funding will reach \$175,000 per year for a five-year commitment.

Funds allocated in 2000: \$32,500.

2. Tomas Ganz, Ph.D., M.D., Professor of Medicine and Pathology, University of California, Los Angeles, School of Medicine, Los Angeles, CA. *Antimicrobial Deficiency of CF Airways Secretions*.

This research project has proposed to identify protein determinants of CF airways colonization by identifying and comparing microbicidal components of non-CF and CF nasal fluids. The studies will examine differences in the number and activity of natural antibiotics, called antimicrobial peptides or "AMPs". Also studies will compare the protein patterns of nasal fluid from CF patients to both non-CF donors and *Staph*-carriers. These two lines of investigation will determine components specifically defective in CF airways. Defective antimicrobials could ultimately be therapeutically replaced to restore the natural antibiotic activity of CF airways secretions.

Amount funded: \$54,000

3. Martin Kharazzi, Ph.D., Research Scientist, Genetic Disease Branch, Department of Health Services in Berkeley, California for the state of California. *Cystic Fibrosis Mutation Frequencies in Hispanic Adults*.

This study seeks to analyze and determine the most frequent CF mutations for Hispanics and other minorities in California in an effort to support a newborn screening process adequate for the cross-cultural population of the state. Currently many mutations common to the Hispanic population are unknown.

Amount funded: \$20,000.

Honorariums

An honorarium is a donation made in honor of a living person.

| | | | | | |
|-----------------|-----------------------------|------------------|---------------------|---------------------|-------------------|
| Kathleen Abeles | Hayden Ellett | George Hawley | Paul Lennon | Barbara Peterson | Andrew Sabatino |
| Richard Abeles | Dr. W. Aubrey Federal, Jr. | Tyler Heavner | Sara Lennon | Stephen Peterson | Joe Senn |
| Chelsea Abound | Mrs. W. Aubrey Federal, Jr. | Abbey Heilman | Ruth Livingston | Erin Phillips | Marilyn Senn |
| Adam Aliotti | Jim Ficklen | Max Heilman | Jennifer Longoria | Jereme Pierce | Rachel Silver |
| Gianna Altano | June Ficklen | Jenny Heit | Alyson Lowery | Kaeti Pierce | Travis Smalley |
| Sadie Anderson | Alanah Fink | Claire Heit | Tom Lufft | Pammie Post | Judy Staggs |
| Lucy Barnes | Jarrold Fischer | Mary Holt | MacDonald Family | Robyn Primack | Robert Staggs |
| Wendy Bauer | Jacob Fraker | David Holt | Nahara Mau | Briauna Red | Henry Steele |
| Brett Bennett | Joseph Fraker | Haley Horn | Sam McDonough | Paul Reschick | Jane Steele |
| Alison Best | Lea Franks | Clark Huddleston | Stacy Melle | Mrs. Paul Reschick | Ana Stenzel |
| Kevin Burleigh | Rebecca Franks | Stephanie Huff | Jonathan Miller | Michael Reuscher | Robin Stevenson |
| Justin Carnie | Judge Fratianna | Michelle Jones | Anna Modlin | Reynolds Family | Street Family |
| Cochrane Family | Peggy Fratianna | Tracy Kiles | Robin Modlin | Jacob Rexrode | Blair Strohn |
| April Cogdell | Emily Fredrick | Ed Kinney | George Montague | Carl Robinson | Adam Thompson |
| Kellie Couch | Jessica Fredrick | Kay Kinney | Mary Montague | Robinson Family | Betty Vitousek |
| Luke Dorman | Mark Ellis Gerow | Michael Kinsley | Alex Moore | Rogers Family | Brendan Wakefield |
| Maxine Eggerth | Ashleigh Godfrey | Amy Kobernus | Kathy Morse | Donna Romano | Devan Wakefield |
| Elyse Elconin- | Alex Hampton | Bill Kolchin | Chuck Nelson Family | Milt Rosenthal | Aaron Waldrum |
| Goldberg | Elizabeth Hampton | Eleanor Kolchin | Kim Nelson | Sarah Rosenthal | Ricky Whicker |
| Danny Ellett | Stephen Hawkins | Eileen Krep | Jacob Osterholt | Dr. Andrea Rothbart | Wine Family |
| | | | Barbara Palys | Siobhan Ryan | Thelma Worthen |

Memorials

These memorials come to us not only for victims of CF but for their families and relatives as well. We extend our deepest sympathy to their families and friends. These gifts have given new hope to children and adults with CF. *Note: Occasionally someone who has died had the same name as a living person.*

| | | | | | |
|---------------------|--------------------|---------------------|----------------------|--------------------|--------------------|
| Erika Alm | Bernice Cappell | Isaac Goldman | Harold Martin | Peter Pinckney | Tony Stewart |
| John Alumi | Raymond Castillo | Howard Goldstein | David McAfee | Jon Prater | Ann Marie Thibault |
| Meghan Andrade | Roy Clark | Helena Goodman | Mac McCallister | Tim Prater | Jeannie Thibault |
| David Armknecht | Nancy Curry | Sherwin Greenberg | Elizabeth McGowan | Joyce Ramming | John Thibault |
| Jodi Armknecht | Donald Davis | Stephanie Halling | Ruth Milovich | Gene Raubuck | Mary Ann Thibault |
| Cara Baysinger | Richard De Giacomo | Angelina Hannas | Jessica Mobley | Allison Roberts | Susan Thibault |
| Bob Beach | Shirley De Martini | Fran Hartman | Jennifer Montgomery | Thomas Rolefson | John Trask |
| Ann Belisle | Delia Derrick | Larry Harvey | John Ross Moran | David Rubin, M.D. | Marge Trask |
| Ann Beltrame | Neva De Vore | Dorothy Herchebroth | Kim Myers | Bill Ruffner | Linda Herr Trojak |
| Nancy Bergin | Cherie Detrick | Gladys Herr | Tom Murphy | Gus Salmont | Joy Villesenor |
| Laurel Bishop-Pipes | Marty Detrick | Karen Johnson | Ida Nelson | Dhea Schalles | Fanch Vogel |
| Clara Borba | Alison Diamond | Kathy Judge-Morae | Kate Nelson | Larry Shaw | Eliconi Vovou |
| Greg Brazil | Vincent Divine | Shirley Kelley | Scott Nelson | Ethel Slater | June Wagner |
| Ted Brown | William Dougherty | Kitty Kious | Nancy Ogden | Tammy Smerber | Christopher Walton |
| Louis Burdet | Emory Edwards | Christopher Kloss | Michele Olson | Charles Smith | Thomas Walton |
| Bob Burnham | Mrs. Emory Edwards | Eva Kulikauskas | Gladys Pearl | Jennifer Smith | Haley Wester |
| Kristi Burnham | Jennifer Eisner | Dawn Longero | Paulette Percoli | Richard Smith | Barbara Widen |
| Kyle Butler | Aldo Fiammango | H. Lane | Clay Perkins | John Southwell | Rudolph Wiesmann |
| William Cady | Stephen Gaggs | Babe Martin | Lucian Pinckney, Jr. | Betty Souza | Edward Winters |
| | | | | Joyce B. Steinmetz | Lena Zucca |

How to Submit an Honorarium or a Memorial in Honor of Someone You Love

Do you have a relative or friend that you would like to honor? Are you searching for the perfect birthday present, wedding or anniversary gift or memorial? Give a gift with lasting impact. Make a donation to Cystic Fibrosis Research, Inc. We'll send a special message to the recipient or to the deceased's family informing them of your contribution if you give us the name and address of the family. 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 occasion of the person you are honoring or remembering to: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043

Become a Tea Sender in 2001!



CFRI's largest fundraiser, the annual Mother's Day Tea, brought in more than \$225,000 in 2000! Thank you to the more than 500 tea senders who sent out cards to their family, friends and colleagues on behalf of CFRI. This money directly benefits CF research and program services serving the CF community. If you did not send tea letters last year, but would like to do so this year, please fill out the action coupon in this newsletter. Remember also, if the spring is too busy a time for you to send out your letters, CFRI will do the mailing for you. Please participate in this wonderful and inspiring event. Do it for the kids and adults whose lives are affected by CF every day! To place your order for tea invitations, contact the office via email at cfri@cfri.org, visit our website: www.cfri.org or call the office at 650-404-9975!

Thank you for
my tomorrow
Gabriel



Gabriel Parodi, age 5, has cystic fibrosis. He is shown here with his cousin and best friend, Kaitlyn, age 8.

Some Books for the Journey *(Continued from page 6)*

CF, the major organs affected, issues related to surgery and CF, transplantation issues, hospitalizations, terminal care, and emphasis on serving different age groups.

I have already used this book several times to compare it to the treatment course recommended for my child. I consider it a free second opinion. It is also helpful when studying aspects of CF that I didn't understand or for doing preparatory research on a topic before meeting with a professional. You won't get the depth here that you might get from researching a topic on-line or at the library, however, you'll get a general synopsis of standard assessment protocols and treatment methodologies for presenting CF complications. While the language used in this book is geared toward the professional, it is clear and accessible. I think this is a helpful reference book to have on hand for any parent of a CF child or adult with CF who wants to have an educated voice in the management of the disease. It is essential for those who do not have access to routine and regular care at CF-accredited CF centers.

Kelsea's Kitchen Quick Fix Recipes, A Collection of Recipes from Cystic Fibrosis Families and Their Friends. For copies send \$11.70 (includes shipping) per book to Kelsea's Kitchen CF Fundraiser, 3437 E. Ripple Road, Camp Verde, AZ 86322.

This is a lovely collection of recipes prepared as a fundraiser for the Cystic Fibrosis Foundation Arizona Chapter. The editors collected recipes from everyone they knew who either had CF or knew someone with CF. It was very fun to read through and recognize contributors' names from either Cystic-L or the CFRI Conference. The volume was not intended to be primarily for people with CF. But maybe because so many of the contributors have CF in the family, many of the recipes are quick, easy and high in fat content. I found several that became favorites for my family. I also loved the helpful hints found at the beginning of each section. Some of you chefs may already be wise to these suggestions, but for me, these tips were new and noteworthy. You will be helping to support CF research every time you purchase a copy. What can be better than that? ■

Action Coupon – Become a Member of CFRI

CFRI is dedicated to sponsoring CF biomedical research and education about CF. When you become a member of CFRI, you join a community of concerned people who work together to fight cystic fibrosis. Your annual dues of \$15 (or lifetime membership of \$50 per person) entitles you to vote on the allocation of CFRI research funds and run for a Board of Directors position. All members also receive CFRI News, a newsletter providing the latest in CF research information and social news to the CF community. To join CFRI, simply complete the Action Coupon below and mail it to our office.

CFRI's mailing list is confidential. We do not sell our list, nor do we give out any names or addresses under any circumstances. Our mail solicitations include our personalized Mother's Day Tea mailing and a year-end Special Gifts request that accompanies the Annual Report. If you receive other solicitations for money, they are from organizations other than Cystic Fibrosis Research, Inc.

-
- Here is my annual membership for \$15 per person.
(Contributions above the \$15 annual subscription rate will help offset costs for those unable to donate.)
- Yes! I want to help. Here is my check for _____.
- Here is my lifetime membership of \$50 per person.
- Yes, I want to send Mother's Day Tea invitations in 2001.
- Please send me _____ invitations!
- Please remove my name from your mailing list.

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|--------|---------------------------|--------------------------------------|
| Name | Relationship to CF Person | Date of Birth (for CF patients only) |
| Street | | |
| City | State | Zip |
| | Telephone | E-mail |

What do you like about our newsletter? _____

What would you like to see us improve in our newsletter? _____

Please list any ideas for future articles, regular columns or subjects you'd like to see featured here: _____

ABOUT CYSTIC FIBROSIS AND CFRI

CF is the most common life-threatening, hereditary disease in the U.S. Twelve million Americans are symptomless carriers of the CF gene. One in 2,300 American children is born with CF.

Symptoms include:

- persistent cough, wheezing or pneumonia
- loose, foul-smelling stools
- heat prostration
- abdominal pain
- excessive appetite, but poor weight gain
- salty-tasting skin
- clubbed finger tips

CF patients suffer from chronic lung disease and digestive disorders which may require frequent hospitalizations. At present, only half of those with CF survive to age 31.

ABOUT OUR FUNDRAISING

Cystic Fibrosis Research, Inc. raises funds through a number of channels:

- Personal mail solicitations
- Memorials and Honorariums
- Grants
- Special fundraising events
- Membership fees
- General donations

CFRI's EMAIL ADDRESS AND WEB SITE

CFRI's email address is: cfri@cfri.org. Use this address to obtain information about our organization, the latest word on cystic fibrosis, or to communicate with our office. Also check out our Web site: <http://www.cfri.org>. See you on the Internet!

ABOUT OUR SERVICES

CFRI offers the following services:

- Research funds awarded to scientists at major medical research centers
- Educational meetings for the CF community
- Annual CF Educational Conference
- Annual CF Retreat for ages 16 to adult
- Family support groups
- CF support groups for ages 13 to adult
- *CFRI News* newsletter
- Email and telephone referrals and support services
- Videotapes of meetings and conferences

ABOUT OUR SUPPORTERS

CFRI is a nonprofit, volunteer organization not affiliated with any other group. Our support comes from the dedicated volunteers and staff. Supporters include:

- Executive Director, Program Services Manager, Outreach Specialist (part-time) and two Administrative Assistants
- Research Advisory Committee of physicians, scientists and members
- Board of Directors and Executive Committee
- Advisory Committees
- General membership
- Mother's Day Tea senders
- Office volunteers

Special Thanks: CFRI wishes to thank PathoGenesis Corporation, makers of TOBI®, for their generous support of *CFRI News*.



Cystic Fibrosis Research, Inc.
2672 Bayshore Parkway, Suite 520
Mountain View, CA 94043

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