Effect of Clarithromycin on Airway Obstruction and Sputum Neutrophilia in Patients with Cystic Fibrosis

By Homer A. Boushey, M.D.
Chief, Asthma Clinical Research Center and the Division of Allergy & Immunology; Professor of Medicine, Department of Medicine University of California, San Francisco

Editor’s Note: Dr. Boushey was awarded a research grant from CFRI in the Spring of 1998 to document whether macrolide antibiotics affect the immune response to lung infection in CF, rather than acting primarily as antibiotics that directly kill bacteria. He hopes to use the data he obtains from the CFRI study to guide the proposal for a larger, multicenter trial.

The question that my research team has been studying with support from CFRI is whether prolonged use of a macrolide antibiotic might have beneficial effects in cystic fibrosis. Our interest in the possible value of “macrolides” derived from three sources. One source was the on-going work of basic science colleagues at UCSF examining how the secretion of airway mucus is regulated in guinea pigs. The second source was clinical research, largely done in Japan, showing that macrolide treatment is effective for other inflammatory diseases of the airways that resemble cystic fibrosis. And the third source was a report of dramatic improvement from prolonged treatment with azithromycin, a common macrolide antibiotic, in a 17 year-old with severe cystic fibrosis.

The guinea pig studies are aimed at defining the cells and chemicals responsible for the profuse secretion of mucus provoked by infection of the airways. In general outline, these studies have suggested that both viral and bacterial infections stimulate bronchial epithelial cells to release “cytokines,” chemicals that affect the activity of other cells. One cytokine, “interleukin 8,” particularly attracts white blood cells (neutrophils) from the blood stream into the airways. On arriving in the bronchial mucosal lining, the neutrophils in turn release “elastase,” an enzyme that can damage or kill bacterial invaders. Another action of elastase is to stimulate mucus glands and goblet cells to secrete mucus. The requirement for infection can be short-circuited by instilling interleukin-8 directly into the airways of a guinea pig. This causes a striking influx of neutrophils into the bronchi and also stimulates the secretion of mucus. These actions are dramatically reduced by pretreating the guinea pig with a macrolide antibiotic, like erythromycin or clarithromycin. What this finding means is that macrolide antibiotics can directly inhibit neutrophil attraction and mucus secretion in guinea pigs.

Adding further to our interest in macrolide antibiotics was a report from another laboratory that these also inhibit interleukin-8 production from cultured epithelial cells directly infected with a virus. These research findings were interesting on their own merits, but were made all the more interesting by the results of clinical studies of treatment of “diffuse panbronchiolitis.” This disease is rare in Japan; even fewer cases have been reported in the United States. Diffuse panbronchiolitis, or “DIP,” has no known cause. Its main feature is inflammation of the smallest branches of the bronchial tree, the bronchioles.

Biopsies show a marked increase in the number of neutrophils around the bronchioles and obstruction of the bronchioles themselves by plugs of mucus. The fluid in the airways contains high levels of interleukin-8. This disease was once thought to be uniformly fatal, marked by progressive worsening of airway obstruction, especially after the airways became infected with pseudomonas bacteria. But treatment with a macrolide antibiotic was serendipitously found to be remarkably effective. It not only arrests progression of the disease, but also dramatically lowers the concentrations of interleukin-8 and the number of neutrophils found in the fluid in the airways. It is still not known whether the (Continued on page 4)
A Letter from the Editor

In the CFRI News Fall 1998 issue, Ann Robinson, CFRI’s Executive Director, announced that our organization has been reexamining its mission, activities and organizational structure. CFRI took on this daunting task to learn how to expand on and improve the services we provide to the CF community. We recognized a need to find an Executive Director who could concentrate on fundraising and organizational development to supplement the work that Ann has been doing in educational development and program services.

We are now happy to report that we have found an extremely talented and energetic Executive Director, Calvinia Williams, who has over ten years experience working with nonprofit organizations. These include, most recently, San Francisco Youth Courts, the American Red Cross Service Center, the United Negro College Fund Pacific Northwest, and Big Brothers and Sisters of the East Bay, among others. Because she has just arrived at CFRI, you will meet and hear from her in our next issue of CFRI News. She will be at all of our functions and in the office daily. If you live locally, stop by the office to say hello, or introduce yourself to Calvinia at one of our functions. Meanwhile, welcome and good luck, Calvinia! It’s great to have you on board.

Ann Robinson, now Director of Education, has been planning the 1999 CFRI Conference to be held this coming September. You’ll find the conference highlights in this issue. CFRI, the International Association of Cystic Fibrosis Adults (IACFA), and the Stanford University School of Medicine are joint sponsors of this event. It promises to be a weekend packed with learning, socializing and inspiration. Also in this issue, Ann encourages readers to participate in our biggest fundraising activity—the Mother’s Day Tea. The joy of this “non-event” is that you can participate no matter where you live.

CFRI’s developments in research continue. You can read about one researcher’s progress in our cover story. You may also read about the allocation of our 1998 research dollars. We are proud to say that an unprecedented amount of money was spent in 1998 on research and research-related activities! In addition to funding unique research studies, we allocated funds to support laboratory research assistants, and we funded a much-needed research assistant/educator position at one California Bay Area CF Center to allow researchers there to spend more time in the laboratory.

In order for our newsletter to offer more for our community, we need to learn who you are. In this issue we’ve inserted a survey which asks who the CFRI News’ readers are, what you value about CFRI News, and which CF topics are of interest to you. We hope you will take a few minutes to complete and send in our survey.

In the summer issue of CFRI News, you will hear from Calvinia Williams, our new Executive Director, in this column. Until then, we ask that you learn what you can about CF and the people who comprise the CFRI community. If you are able, we ask that you reach out to others in the community, that you continue to support our research and educational efforts, and most importantly, that you take care of yourself.

Sincerely,

Francine Bion
CFRI News Editor
GRASPing for the Stars

When Alanah Fink is not practicing her cheers for her San Jose middle school basketball team or gearing up for an upcoming school trip to Washington, D.C., the 13-year-old is on tour with the GRASP Foundation. GRASP, which stands for Gaining Respect and Awareness by Sharing Potentials, is a nonprofit group that visits Santa Clara County elementary schools, businesses and churches. The group’s goal is to create awareness of people with disabilities by increasing the understanding of their conditions. They help to change attitudes by replacing myths and fears with facts and empathy, according to GRASP executive director Margie Monroe.

The participants spend a full day with elementary school children, discussing how they cope with their disabilities, what experience they’ve had and what products help them, such as TDD machines and wheelchairs. Alanah is one of the few young adults on the five-person panel, but she is happy to participate because she says the children seem to relate better to someone near their age.

“I’ve been in GRASP for a year,” Alanah says, “and I’m surprised how much kids know about different disabilities.” She found that a lot of kids have asthma. “This makes it easier to explain what cystic fibrosis is. The medications are similar to the ones they take for asthma,” she says. Alanah used to avoid talking about CF, but now she’s more comfortable discussing it. “GRASP really helps me talk about it. And I’ve learned different ways to explain about CF to different people.”

If you’d like more information about GRASP, contact GRASP Foundation, 6940 Santa Teresa Blvd., Suite 6, San Jose, CA 95119-1345, 408-225-6134.

More than Just Horsing Around

What does Strawberry, a 12-year-old foxhunting horse, know about CF? Probably not much, but he helps Katelyn Salmont, also 12, breathe better. In fact, Katelyn, her dad and her mom think horseback riding helps to keep her lungs clear. “There is percussion involved when she jumps the horse. On the days she rides, she doesn’t need to do her therapy vest,” her father Randy says.

And that’s just about every day. The ranch where Strawberry lives is right near Randy’s house in Valencia, California. “I love Strawberry and riding him helps me breathe,” Katelyn says. “When I broke my wrist and couldn’t ride, I got very congested. Riding makes me feel a lot better.”

Horseback riding is her true passion, one she learned from her mother and her aunt.

(Continued on page 6)
effectiveness of macrolides as a treatment for DIP means that they have some other, non-antibiotic action that reduces inflammation and mucus secretion, or whether they treat an infection that simply has not yet been identified. The idea that they may have an additional action seemed more likely after a study of children with bronchiectasis showed that macrolides were more effective in reducing the purulence and volume of sputum than were other antibiotics with greater potency against the bacteria found in the children’s airways.

We had already begun to think that the effectiveness of macrolides in cystic fibrosis should be examined when the case report was presented. This report described a 17 year old whose airway disease was so severe that he was considered a candidate for lung transplantation. After a long course of treatment with azithromycin, his pulmonary function and oxygen improved to where he could be taken off the transplant list.

Studies of laboratory animals, clues from the treatment of other diseases, and a single case report can only make a case that an idea is worth pursuing. We are pursuing the idea that treatment with a macrolide antibiotic might benefit cystic fibrosis in a blinded, controlled trial of the effects of twice-daily treatment with clarithromycin, a potent, well-known antibiotic. We are examining the effects of treatment not just on the symptom of sputum production and on pulmonary function, but also on the numbers of neutrophils and on the concentrations of mucin, of neutrophil elastase, and of interleukin-8 in the sputum the patients cough up after they inhale a standard aerosol of saline. In this standardized, disciplined way, we hope to gain some insight as to whether a treatment that has long been available to us for infections might have some action of particular benefit for cystic fibrosis. If our small trial confirms the promise, we hope further that it will prompt a more definitive trial in a larger number of patients and will perhaps also prompt research on how macrolides act to produce this benefit, so that more powerful, selective drugs can be made. 

Savory Solutions: A Collection of Unique Recipes Benefiting Those with Cystic Fibrosis

Written and edited by Kim Payne, © 1998. For information, write P.O. Box 1576, Stillwater, OK 74076-1576

Review by Kathleen Flynn

I was impressed with this small collection of recipes. Because I live in a household of picky eaters (whose favorite meals are take-out!) my frustration with the dinner hour is legendary. My son with CF, Devin, has made an art form of sniffing out hi-calorie protein supplements and, if discovered, rejecting the meal in its entirety. So it is rare that I am inspired to try again to help him gain weight.

This small cookbook did, however, inspire me. It is comforting to read a cookbook composed for the CF person. The tidbits of advice are all very relevant to those of us struggling with weight gain, malabsorption and the eating blues. The author includes various charts comparing powdered and liquid food supplements and detailing specific information about sodium and dairy intake. There is a wonderful section entitled “Comfort Me,” containing recipes for the sick days, specific to certain ailments. The recipes are simple and straightforward, submitted mostly by people who have CF. These are truly for the people who spend a lot of time with health care and do not have hours to spend in the kitchen! Overall the book offers a very supportive attitude for those feeding the CF person, and indeed, all proceeds made from the book are donated to CF education and research.

My only hope is that this book is a work in progress. I would love to see more additions in all of the categories, and also a section for those with CF who cannot tolerate the high-fat diet, full of recipes with high protein contents but lower on the fats. Also, sections for children and those with diabetes could be added. I encourage our readers to purchase this handy recipe book and not only work with it, but add to it and enrich it. In time, it could be THE definitive CF cookbook. For your copy, send $10.00 to Savory Solutions, P.O. Box 1576, Stillwater, OK 74075-1576 or call (405) 372-2492.

Cystic Fibrosis in Adults


James Yankaskas, M.D. is Professor of Medicine, Director, Critical Care Medicine Program; Co-Director, Adults Cystic Fibrosis Program, University of North Carolina School of Medicine, Chapel Hill, North Carolina.

Michael Knowles, M.D. is Professor of Medicine, Director, Adult Cystic Fibrosis Program, University of North Carolina School of Medicine, Chapel Hill, North Carolina.

Review by Ann Robinson

This newly published textbook is the first of its kind for treating cystic fibrosis (CF) in adult patients. Until recently, the clinical expertise for treating CF was developed by pediatricians. The increased longevity of the CF population has resulted in more age
and disease-related medical problems that rarely appear in childhood. Because approximately one third of all patients with cystic fibrosis are now at least 18 years old, CF has grown into an adult disease, an evolved and separate entity where new medical challenges are evident.

*Cystic Fibrosis in Adults* represents a benchmark in the 60-year medical history of CF, and is a strong statement that the care of adults is different from the care of children. This book, a collection of articles by some of the most renowned CF clinicians and researchers, was written as a comprehensive text for diagnosis and care of adults with CF. It is directed at physicians, nurses and respiratory therapists who are developing expertise in the many aspects of the adult presentation of this disease. However, experienced lay persons, adult patients with CF and parents of children and adults with CF can benefit from using this book as a reference. It offers a unique study into the disease where one can read and form questions for the medical professionals who are treating adults with cystic fibrosis. Of particular interest to me were the extensive charts and discussions on phenotype and genotype and the different manifestations of CF based on a person’s alleles. I also found the information on antibiotic treatment (both oral and I.V.) and the major complications of CF highly useful. Chapter 11 included new therapeutic strategies for CF lung disease, which offers an in-depth discussion of gene

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### Become a Mother’s Day Tea Sender for CFRI

This year’s Mother’s Day Tea fundraiser promises to be the best ever! No matter where you live, you can join in “the tea.” Tea senders address and send invitations to their friends and relatives inviting them to an “imaginary tea.” The invitation includes a donated Bigelow herbal tea bag, information about cystic fibrosis and a request for a donation to CFRI. The tea is our most successful fundraiser and is one of only two direct mail solicitations sent annually to CFRI’s donors. Please call us to become a tea sender on behalf of a friend or loved one with cystic fibrosis.

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First cousins, Chelsa Aboud and Briauna Red happily appear on the front of this year’s tea invitation enjoying their tea party. Chelsa and Briauna, granddaughters of Dellene Ott, both have cystic fibrosis. Please join them in having a cup of tea and sending tea invitations on their behalf.
Your Donations of Cards and Time Are Helping!

A Note from Pat Flynn, CFRI’s Gift Tag and Note Card Coordinator

As I reflect on my first year creating note cards and gift tags for CFRI, my feelings are best expressed by WOW! PHEW! and HELP! We successfully identified new outlets this year, discovered enthusiastic sellers and realized a potential for money making that didn’t exist before. One tea held on a Sunday afternoon in October brought in $1,000. Suppose a dozen people throughout the state or country hosted such teas—incridible thought! Craft fairs and school holiday events brought in additional income. CF awareness week in Sacramento provided another showcase for our cards, as did a student fundraiser at Northern Ohio University. Most important, CFRI members took baskets of cards to offices, schools and clubs, and sold them to friends and neighbors. An announcement on the Internet as well as a notice in the San Jose Mercury News’ Actionline is now bringing in a huge supply of cards as well as many inquiries. People like the idea of recycling and the project raises community awareness about CF.

Plans for the Coming Year

Myrtie Boore, the dedicated instigator of this project passed away last August. She left me an ample supply of cards with which to start. I’ve come to realize how tirelessly she worked. In the coming year, I will be establishing a notice in the San Jose Mercury News’ Actionline is now bringing in a huge supply of cards as well as many inquiries. People like the idea of recycling and the project raises community awareness about CF.

In addition to the baskets on display in the office, we will be featuring seasonal greeting cards. Look for Valentine’s Day, St. Patrick’s Day, Easter and Passover cards in the spring, followed by Mother’s Day and Father’s Day, graduation and wedding cards as... (Continued on page 7)

Some Books for the Journey (Continued from page 5)

therapy for CF. Their explanations made much of the current research news more accessible for me.

Cystic Fibrosis in Adults is an excellent reference book. In writing the book (it was an eight year process), care was taken to confirm the accuracy of the information presented and to describe generally accepted practices in treating cystic fibrosis. However, it does not mention all treatments currently being utilized in the more progressive Cystic Fibrosis Treatment Centers, and one CF adult commented that the treatment plans presented were not aggressive enough. There is much current research evidence that suggests that the more aggressive treatment centers are having better results. ■

Note: Please be advised that although this text offers instructional information on dealing with CF, it is in no way intended to replace your physician’s treatment plan.

Good News (continued from page 3)

In addition to jumping Strawberry in competitions, Katelyn rides a pony named Trixie through obstacle course races. She also trains horses at the ranch. Randy says, “It’s quite a sight to see this 60-pound girl telling this huge animal what to do.”

When she’s not “horsing” around, Katelyn is a self-professed computer nerd. She loves chat rooms—“Just like talking on the phone!”—and uses her time in front of the PC to inhale her meds, like TOBI.

The family maintains a charitable organization which was established by Katelyn’s great-grandfather and his wife. Last year, the foundation donated a $10,000 grant to CFRI exclusively to support the newsletter. Randy is thrilled with the donation. He says, “The money definitely went to the right place.” At CFRI we are equally thrilled and tremendously grateful.

On-the-Job Fundraising

Every year, Tom Moran, a vice president at Wells Fargo in Madera, California, encourages his co-workers to designate their United Way donations to Cystic Fibrosis Research, Inc. “I found that a lot of people don’t have a favorite charity or just don’t know where to donate their money,” says Tom. “At meetings, I explain about CF and how it is a great cause.” Then, Tom shows them how they can earmark their money for research. “At Wells Fargo, we are encouraged to give to United Way with donations that come out of every paycheck. We designate which charities the donations should go to.” Tom suggests people designate their money to go to CFRI. His technique has proved successful over the six years he’s been doing this. At his last branch managers meeting, the donations tallied $2,500!

Tom has a special reason why CFRI is his charity of choice: his stepdaughter Laura Woods’ son has CF. Logan is seven years old and in first grade at a Modesto elementary school. Laura and her mother, Gloria Moran, think Tom’s on-the-job fundraising is wonderful.

“Every once and a while, I bring Logan in with me to the office. People can meet him and really see where—and to whom—their money goes, says Tom. “It makes them feel good to help someone they know.” Some co-workers have actually increased their donations after meeting Logan, while five others have made additional personal contributions. Keep up the good work, Tom! And thanks to all the Modesto Wells Fargo contributors! ■
Annual CF Conference Invitation

You are invited to attend the 12th Annual CF Conference to be held on September 10 – 12, 1999 at the Fairmont Hotel in San Jose, California. This year’s conference is sponsored by Cystic Fibrosis Research, Inc. (CFRI), the International Association of Cystic Fibrosis Adults (IACFA), and the Stanford University School of Medicine (SUSM). CME units will be offered through SUSM.

Topics Include:

- An Update on Cystic Fibrosis Research
- A Genotype/Phenotype Research Update (how gene type can affect health in CF patients)
- Lung Clearance Techniques
- Secondary Complications in Cystic Fibrosis Patients:
  - Diabetes, Liver Issues, Osteoporosis, Gastrointestinal Problems and Cancer
- “Ask the Experts” Panel Discussion
- A Workshop on Issues Surrounding Lung Transplantation
- Panel Discussion on Personal Views of Lung Transplantation
- The Doctor/Patient Relationship (two physicians will play the role of patients and two patients will play the role of physicians)
- Panel Discussion on Psychosocial Issues in Cystic Fibrosis
- Panel Discussion on the Comparison of CF Treatments Around the World
- Sibling Issues for Families Having Children with Cystic Fibrosis
- A Workshop on Newborn Screening for Cystic Fibrosis

Support Groups for:

- Parents and Family Members Having Children With Cystic Fibrosis (broken down into age groupings)
- Adults with Cystic Fibrosis
- Couples (at least one must have CF)

Registration fees include conference tuition, reference materials, five meals and a reception:

- Adults with CF age 16 or above - $125
- Family Members of People with CF - $ 125
- People in the above groups who are CFRI members - $ 115
- Nurses and Health Care Professionals - $175
- Physicians - $250

A few scholarships are available for adults with CF and families having children or adults with CF. Please contact the CFRI office if you are interested.

For adults with CF: Because of the risk to others, CFRI prohibits individuals from attending this conference if their sputum cultures show *Burkholderia cepacia*, methicillin-resistant *Staphylococcus aureus* (MRSA), or any type of bacteria which is resistant to all antibiotics. In order to attend, you must complete a sputum culture between July 15 and September 1, 1999, and you must have been free of these bacteria for the past year. We must receive a completed medical release for each participant with CF for registration to be final.

For a conference brochure and application, contact the CFRI office at:
560 San Antonio Road, #103
Palo Alto, CA 94306
phone: (650) 856-0546
e-mail: cfri@cfri.org
Lucy Marsh Memorial

Lucy passed on this fall surrounded by family and the loving staff at Lucile Salter Packard Children’s Hospital at Stanford. For many of us her courage and laughter put into perspective what is truly lasting and important in life. She was her father’s (George Marsh) best drum (CPT), her mother’s (Cynthia Lenssen) first acupressure client, and her sister’s (Emily Marsh) best friend.

Lucy was a productive artist, drama queen, philosopher, poet, lover of Truth, frequently challenging and stubborn, a sharpshooter on the basketteball court, an avid gourmet, and singer and dancer. She lived a much bigger life than the one with the CF limitations, grabbing hold of things and people that interested her and pursuing them with intense inquisitiveness. She dreamed of a life after transplant that would include ice skating, college, time with friends, marriage, three kids!, a lucrative career with writing and acting on the side, a basset hound, endless travel and time to help others in need. Lucy’s spirit lives on in the inspiration, energy and zest for life which she infused into all who knew her.

—Cynthia & Emily

Biomedical Research Funded in 1998

Editor's Note: CFRI funds cystic fibrosis research in two cycles every year. Last year the following researchers and their proposals were recommended for funding by the Research Advisory Committee (RAC) and approved by the Board of Directors and General Membership of CFRI. The total funds awarded for 1998 amounted to $289,114.

Spring Cycle:

1. Homer Boushey, M.D., University of California at San Francisco, Principal Investigator. Effects of Clarithromycin (Biaxin) on Sputum Production and Markers of Inflammation in Patients with Cystic Fibrosis; a pilot study.

   Boushey’s goal is to obtain data to guide the proposal for a multicenter trial to document whether macrolide antibiotics affect the immune response to lung infection in CF, rather than acting primarily as antibiotics that directly kill bacteria. (see cover story)
   Amount funded: $35,000

2. Dieter Gruenert, Ph.D., University of California at San Francisco, Principal Investigator. Small Fragment Homologous Replacement (SFHR) of Genomic CFTR in Vivo.

   The prospect of directly correcting the mutant portion of disease-causing genes is one of the main goals of gene therapy. SFHR is an alternative method to classic gene therapy approaches that use adenoviral vectors and transfer of CFTR–DNA by liposomes. SFHR uses small fragments of DNA to replace CFTR sequences. This approach has been successful in airway epithelial cells, and other cell lines, including a nasal polyp cell line. This is follow-up funding for Dr. Gruenert who is now advancing from the cellular level to study this transfer technique in mouse nasal airways with the goal of generating transgenic animals.
   Amount funded: $30,000

3. Christine Haws, Ph.D., University of California at San Diego, Principal Investigator. Cell Specificity of Bicarbonate Permeation through CFTR.

   In the pancreas, malfunction of CFTR impedes bicarbonate passage that is necessary for the pancreas to perform its function of neutralizing stomach acid. The application of a patch clamp technique offers hope of rapidly eliciting the mechanism.
   Amount funded: $40,000

(Continued on page 9)

Some wonderful Lucy quotes:

“Go away!”
— age 20 months during her first hospitalization

“You can’t mix work with play!”
— age 3 when too busy to stop for chest physiotherapy

“…you can be sad and cry over my death, you can feel sorry for me and you can wish as many times as you want that I hadn’t died, but I’m happier than I ever have been, and I’m always with you whether you know it or not. My love surrounds you and protects you for all eternity.”
— age 13 years, from a short story Lucy wrote
Biomedical Research Funded in 1998  (Continued from page 8)

4. John LiPuma, M.D., Allegheny University of the Health Sciences, Philadelphia, PA, Principal Investigator.  
Epidemiology of Burkholderia Cepacia in Northern California.

The specific aims of this project are to a) determine the frequency with which misidentification of B. cepacia and related bacteria may be occurring in Northern California, and b) by using bacterial genotyping methodology, investigate the molecular epidemiology of B. cepacia and related bacteria in Northern California.  This is a collaborative study involving the Northern California CF Centers and their laboratories.  
Amount funded: $32,883.

5. Fred Lorey, Ph.D., Chief of Program Development and Evaluation Section of Genetic Disease Branch, California State Department of Health Services.  Attendance at the Fifth International Conference on Neonatal Screening for Cystic Fibrosis in Paris, September, 1998.  
Amount funded: $1,487

6. Stipends for research assistants studying CF in the laboratories of:  
• Children’s Hospital at Oakland Research Institute, Oakland, California  
• Stanford University Medical Center, Stanford, California  
Amount funded: $10,746

Fall Cycle:

1. John LiPuma, M.D., Allegheny University of the Health Sciences, Philadelphia, Pennsylvania, Principal Investigator.  Gram Negative Epidemiology Studies of Seven Northern California CF Treatment Center Laboratories.

This request is for a 6-month extension of his grant funded in the Spring cycle, to include polymerase chain reaction (PCR) (genetic) as well as sputum culture tests for the presence of B. cepacia.  
Amount funded: $23,000

2. Richard Moss, M.D., Director of the Cystic Fibrosis Center, Lucile Salter Packard Children’s Hospital at Stanford University Medical Center, Stanford, California.  
Research Nurse/Educator.

This one-year grant will fund a position for a Research Nurse/Educator for the Cystic Fibrosis Center at Stanford University Medical Center to facilitate clinical research and possibly to facilitate regional collegial research.  
Amount funded: $64,000

3. Neal Schiller, Ph.D., University of California at Riverside, Principal Investigator.  Antibacterial Activity of Protegrin: A Novel Therapeutic Agent vs. CF.

Dr. Schiller will study a new type of antibiotic protegrin called PG-1, to determine the mechanism of action by which it kills pseudomonae and whether this depends on the presence of certain cell surface components which may differ from the components of B. cepacia.  Characterizing the bactericidal action of PG-1 against Pseudomonas aeruginosa and B. cepacia, as well as the mechanism of bacterial resistance to PG-1, are essential steps in determining the potential usefulness of PG-1 as a therapeutic agent for CF patients.  
Amount funded: $37,000

4. Student stipends were given to the following laboratories with the stipulation that they be used directly for cystic fibrosis research.  Total amount of awards: $14,998  
• University of California at San Francisco  
• Children’s Hospital Oakland Research Institute, California  
• Stanford University Medical Center, Stanford, California
An honorarium is a donation made in honor of a living person. 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 died had the same name as a living person.

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, 560 San Antonio Rd, Suite 103, Palo Alto, CA 94306-4349
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.

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.

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☐ Here is my annual membership for $15 per person. (Contributions above $15 annual subscription rate will help offset costs for those unable to donate.)
☐ Yes, I want to send Mother’s Day Tea invitations in 1999.
☐ Yes! I want to help. Here is my check for__________.
☐ Please send me _______ invitations!
☐ Here is my lifetime membership of $50 per person.
☐ Please remove my name from your mailing list.

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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

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 CFRI 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
- The Cackler, a newsletter for children
- 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 dedicated volunteers and staff. Supporters include:

- Executive Director, Director of Education and two administrative staff
- 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 Genentech, Inc., makers of Pulmozyme®, and Pathogenesis Corporation, makers of TOBI®, for their generous support of the CFRI News newsletter.

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