



CYSTIC FIBROSIS CENTER NEWS

The Cystic Fibrosis Foundation Clinical Care Guidelines

Frequency + Aggressive Care=Better Outcomes



Over the past 40 years the median age of survival for persons with CF has risen from less than one to more than 30, with children born in the 1990's expected to reach their 40's or even 50's (the eldest person with CF now in the Cystic Fibrosis Foundation Registry is 78!). These remarkable increases in life span and quality of life are largely credited to the establishment of specialized care centers, improved enzymes, drugs and treatments, and the standardization of care management that the Cystic Fibrosis Foundation (CFF) has championed. The first CFF Clinical Practice Guidelines were published in 1989 "to promote a uniform level of care and teaching services at CF Care Centers and to provide a general framework for good patient care." Goals of the current Guidelines, published in 1997, are to achieve optimum health status and to anticipate and treat physical and psychosocial complications of CF. Primary objectives are to: 1) ensure optimum care; 2) facilitate access to pertinent medical resources; 3) coordinate care among specialists and primary care physicians and 4) support quality of life and independence for each patient. Frequent contact with the CF center is necessary to accomplish these objectives.

Designated CFF Centers provide a multidisciplinary team that delivers expert care management, oversight and education that includes medical, nursing, nutritional, psychosocial and respiratory care and support. The CFF Guidelines include diagnostic and treatment recommendations in addition to a comprehensive education program to promote optimum understanding of CF, adherence to treatment plans and methods of coping with the demands of CF. Although data on the relative effectiveness of models of care are limited, the strong association between the establishment of comprehensive CF Care Centers and improved patient outcomes, and recent studies associating aggressive care with improved survival and higher functioning, validates the CFF's multidisciplinary Center approach.

This issue provides a summary of the CFF Clinical Care guidelines and outlines the objectives and components of the routine monitoring and care maps that are the gold standard for Center-based care.

2004 CF EDUCATION DAY AT LPCH

SATURDAY, MARCH 6, 2004

SEE PAGE 7 FOR DETAILS!

Research Supports Aggressive Care

Frequent monitoring and aggressive treatment appear to reduce the frequency and duration of chronic infection and may delay the progression of CF lung disease. Inflammation and infection are present in the CF lung even when a person appears—or feels—well. Regular visits help the CF team identify changes and intervene in a timely manner.

A growing list of studies documents the benefits of frequent monitoring and aggressive therapy. A January 2003 study in the journal *Chest*, based on the Epidemiological Study of CF patient registry, found substantial differences in disease severity between

centers with the highest and lowest clinical status: centers with the highest average lung function and best nutritional status had significantly more frequent clinic visits, lung function tests, and sputum cultures, in addition to more and longer interventions, especially IV antibiotics. The high median age of survival in the Danish CF population (over 40, compared to 32 in the US) is often attributed to a medical system that provides persons with CF monthly clinic visits, aggressive treatment of infections and quarterly IV antibiotic courses for persons chronically infected with *Pseudomonas aeruginosa*, regardless of symptoms.

Outcomes & Significant Correlates to Outcomes in Centers With Highest and Lowest Health Indicators

Outcome Measures & Correlates Over 24 Months	6–12 Years Olds		13–17 Year Olds		Adults Over 18	
	Top Quartile	Lowest Quartile	Top Quartile	Lowest Quartile	Top Quartile	Lowest Quartile
FEV1 % Predicted	93%	74%	85%	62%	65%	50%
Weight for Age %	35%	31%	33%	20%	37%	30%
CF Clinic Visits (#)	11.7	10.6	11.4	10.9	9.7	8.6
Spirometries (#)	11.1	9.3	12.6	8.9	10.5	6.9
Sputum Cultures (#)	5.7	3.6	5.3	4.4	5.3	4.7
IV Antibiotics (#)	1.8	1.4	1.8	1.5	1.7	1.6
Median Duration, days	18.7	15.5	17.0	16.0	17.7	16.0

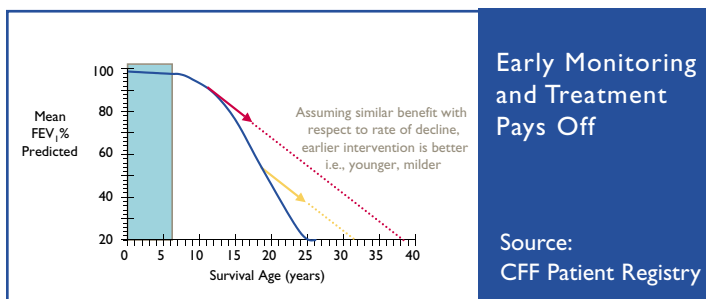
- 1 Johnson, C, Butler, SM, Konstan, MW, Morgan, W, Wohl, ME, "Factors Influencing Outcomes in Cystic Fibrosis", *Chest*, Vol 123, pp20-27 January 2003.
- 2 Frequency is over a 24-month period for persons with FEV1 percent predicted of 40–69%; similar differences were observed across age groups and disease severity.

The CFF has launched an initiative to raise the standard of CF care by identifying best practices and increasing use of proven therapies. Bruce Marshall, M.D., CFF Director of Clinical Affairs asserts that consistent and aggressive use of proven therapies and CFF guidelines could add 5 to 10 years to average CF survival rates over the next 5 years. At the 2003 NACFC conference, LPCH Center Director Rick Moss discussed the powerful impact on survival of even small decreases in the rate of lung function decline, particularly at young ages. Achieving improved outcomes requires a strong partnership between patients, families, and the CF team.

Frequent Routine Care is Key

The health care needs of persons with CF are complex. Routine monitoring allows physicians to identify trends and significant changes that may not be apparent to the individual, family or even a physician who only sees a few persons with CF a year. Few physician offices have American Thoracic Society compliant respiratory therapy and lung function testing programs, CF-knowledgeable nutritionists, social workers and laboratories with the specialized resources needed to identify CF-specific microorganisms and determine the most effective drug synergies and new treatment modalities.

CF affects individuals in unique ways. Intensity and frequency of care varies due to many factors, and the Guidelines must be interpreted to meet each person's unique needs. Nonetheless, research is finding that frequent monitoring and aggressive care result in better outcomes. The Guidelines define the standard of care for routine and periodic evaluation and management by the multidisciplinary CF team.





The CFF Clinical Care Guidelines

Recommended Care	Minimum Frequency	
	Children	Adults (Ages 18+)
Routine Clinic Visit for assessments, interventions, monitoring, education & counseling	Every 3 months or more often as indicated	Every 3 months or more often as indicated
Sputum culture & sensitivity testing	Annually plus before exacerbations or clinical change	Every 3 months (but in no event less than annual)
Pulmonary Function Testing		
Spirometry	Every 3–6 months	Each clinic visit
Complete pulmonary function test (lung volumes, pre/post bronchodilator, etc.)	Annual	Annual
Exercise testing	As indicated	As Indicated
Nutrition Evaluation		
Height & weight	At each clinic visit (3 mo)	Weight at each visit
Mid-arm circumference	Annual	
Triceps fat fold thickness	Annual	
Anthropomorphics, caloric intake, evaluation	Annual	Annual
Nutrition & dietary education	Annual	Annual
3-day Fat Balance Test	As indicated	Upon diagnosis
Chest Radiograph (X-Ray)	Stable: Every 2–3 yrs Frequent infections or declining PFTs: at least annually During pulmonary exacerbation	Stable: Every 2–3 yrs Or as indicated by signs/symptoms During pulmonary exacerbation
Oximetry (hemoglobin saturation)		
Resting	Every 3 months	Each clinic visit
During exercise	As indicated	As indicated
During sleep	As indicated	As indicated
Psychosocial Evaluation		
Monitoring/focused	At each clinic visit	At each clinic visit
Comprehensive	Annual	Annual
Laboratory Tests		
Complete Blood Count (CBC)	Annual	Annual
Vitamin A & E	Annual	Annual
Vitamin D	Annual, preferably in Fall	Annual, preferably in Fall
Antibody screening for ABPA (IgE)	Annual	Annual
Liver function tests	Annual (full work up if abnormal)	Annual (full work up if abnormal)
Albumin	As indicated	As indicated
Electrolytes or Acid-based Status	As indicated	As indicated
Prothombin time (clotting)	Annual after age 9–10	Annual
Pubertal development staging	At age 16+	
Baseline testosterone	As indicated	As indicated
Menstrual assessment	Annual	As indicated
Bone Density (DEXA scan)	Baseline no later than age 18, earlier based on risk assessment (steroids, malnutrition)	Baseline then, every 2–5 years if normal, and annual if at risk
Genetic Counseling	At diagnosis & as requested	As needed
Oral Glucose Tolerance Test (OGTT) for Diabetes	Ages 10–16: Every 2 yrs Ages 16+: Annual	Annual
Patient Education (respiratory, nutrition, fertility, etc)	Ongoing	Ongoing
Multidisciplinary Comprehensive Team Evaluation	Annual	Annual

Additional Guidelines for Common Complications

CF-Related Diabetes		
Hemoglobin A1c	Every 3 months	Every 3 months
Dilated eye examination	Annual	Annual
Urinalysis	Annual	Annual
Home glucose monitoring	Ongoing	Ongoing
Chronic Antibiotic Use		
BUN & Creatinine	After each course	After each course
Audiology (hearing test)	Every 2–4 courses	Every 2–4 courses
Chronic Prednisone Use (more than 3 months)		
Oral Glucose Tolerance Test for Diabetes	Every 6 months	Every 6 months
Ophthalmology	Annual	Annual
High Dose Ibuprofen Therapy		
Pharmacokinetic testing	Initially then 2 years or 25% weight change	Initially then 2 years or 25% weight change
BUN & creatinine	Initially then each 6–12 months	Initially then each 6–12 months

Source: Cystic Fibrosis Foundation

Components of the CFF Care Map

Physician Visits

Quarterly visits with the CF physician are recommended, with more frequent monitoring for high risk conditions. CF centers track health data over time, allowing detection of subtle changes and early intervention. Regular visits with primary care physicians and other specialists are important to manage routine and specialized health needs. At each CF visit

physical assessments are performed to monitor growth, lung function, and nutritional status. Quarterly monitoring provides reliable and useful data to assess health and reinforce patient education and adherence to demanding care protocols. Comprehensive annual visits provide thorough assessments of health status and treatment plans.

Common Conditions Warranting More Frequent Care

Condition

1. Acute pulmonary exacerbation
2. Respiratory failure/pre-lung transplantation
3. Massive or persisting hemoptysis (coughing up blood)
4. Pneumothorax
5. Malnutrition (Ideal Body Weight less than 85th percentile)
6. Diabetes Mellitus
7. Variceal bleeding secondary to CF; cirrhosis
8. Gastrointestinal complications
9. Sinusitis requiring surgical intervention
10. Psychosocial problems
11. Pregnancy

Estimated Incidence in CF

	Children	Adults (Ages 18+)
1. Acute pulmonary exacerbation	0.2%	1.4%
2. Respiratory failure/pre-lung transplantation	0.1%	1.8%
3. Massive or persisting hemoptysis (coughing up blood)	32.0%	44.3%
4. Pneumothorax	2.5%	16.2%
5. Malnutrition (Ideal Body Weight less than 85th percentile)	5.6% (elevated LFT)	5.8% (elevated LFT)
6. Diabetes Mellitus	3.4% (combined)	3.4% (combined)
7. Variceal bleeding secondary to CF; cirrhosis	None reported	More than 10%
8. Gastrointestinal complications		
9. Sinusitis requiring surgical intervention		
10. Psychosocial problems		
11. Pregnancy	185 in 2002	

Source: CFF Patient Registry

Nutrition

The importance of nutritional status in CF to long-term survival is well documented. Achieving each person's genetic potential for nutrition and growth, and prevention of malnutrition are the ultimate goals. Frequent monitoring of "anthropometrics" (height, weight, triceps fat fold and mid-arm circumference) and an annual comprehensive assessment of caloric intake and eating habits are the standard. More frequent visits and aggressive intervention are recommended for persons at nutritional risk (defined as an Ideal Body Weight of less than 90%). Periodic tests monitor vitamin absorption, liver function, and bone disease, as well as screening for CF-related diabetes (which increases risks by 2.5). All of these complications increase with age.

Respiratory

Regular spirometry provides a "baseline pulmonary status" so that exacerbations can be readily identified and treatment effectiveness measured. Treatment is generally indicated for more than a 10% decrease in baseline FEV1 or 3% decrease in oxygen saturation. Routine sputum cultures identify the many microorganisms found in CF that have significant implications

for clinical management and infection control. Labs must be able to distinguish these organisms and provide extended susceptibility panels and synergy testing. Annual comprehensive lung function tests identify changes that guide treatment decisions and care management.

Social Work

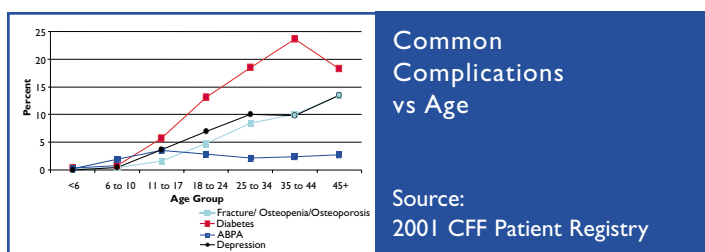
The CF social worker anticipates and treats social and emotional concerns by providing psychosocial support, advocacy and assessment. Expertise includes counseling, financial issues, career planning, health insurance, and employment accommodations (e.g. dealing with employment discrimination, the Family Leave Act, disability, family planning & pregnancy). An annual review helps to anticipate and resolve issues to facilitate day-to-day management of CF.

Nurse Coordinators

Nurse coordinators review medications, identify risk factors that need physician follow-up and discuss needs such as home care management and ports. They monitor the timing and ordering of routine tests and are available by phone to discuss signs and symptoms and help with medication management issues.

Take Responsibility: HELP US TO HELP YOU!

Evidence is mounting that aggressive monitoring and treatment results in better outcomes for CF. Our team is here to ensure that you receive the care required to maintain and achieve your highest potential level of health. Timely routine care and annual assessments, in conjunction with appropriate and aggressive treatments, enable us to promptly identify and treat exacerbations and minimize declines in functioning.





Frequently Asked Questions



Carl Robinson, a computer specialist, has asthma, ABPA and CF.

Center Director Rick Moss responds to questions often asked about the CFF Guidelines and the purpose of the standard care management protocols:

Why are quarterly visits important?

These visits function as an “early warning system” for CF-associated problems that are often detectable before symptoms occur. They also help us to help you manage your medications and treatment regimens more effectively.

If I've been in for a sick visit, should I still come in for a scheduled quarterly visit?

Yes, although the interval to next visit will depend on the specific situation being monitored or treated. We want to see you when you're healthy so that we know your baseline data.

If I'm not feeling sick, why do I need a sputum sample?

A recent sample allows accurate intervention if you do get sick subsequently. Organisms and their antibiotic

sensitivity can change, sometimes dramatically, over relatively short periods of time. It also helps us maintain good infection control in the clinic setting and allows us to inform you when you need to be more careful about cross infection.

Why is an annual PFT test necessary?

While the information in the clinic lung function test (spirometry) is valuable, it is incomplete. For example, spirometry cannot tell us whether a reduction in function is due to obstruction, restriction (e.g. pneumonia or chest wall problem) or both. Complete annual PFTs address these and other aspects of CF lung disease and sometimes result in changes in therapy.

When should I call the doctor or come in for a sick visit?

We encourage you to come in when in doubt, since timely care minimizes declines in lung function. Other reasons to contact us include a change in symptoms, reactions to or a need to change medications, or question regarding your health! Call the Nurse Coordinator first to discuss the urgency or if you have a question about the need to come in.

Don't I increase my exposure to “bad bugs” if I come for a clinic visit?

We structure our clinic visits to minimize contact between patients and optimize hygiene of the environment and equipment. If you have doubts about advisability of a clinic visit, call the Nurse Coordinator and discuss your concerns.

FLU ALERT!!!

We encourage you to visit the U.S. Centers for Disease Control excellent web page on all aspects of the the flu at <http://www.cdc.gov/flu> for complete and accurate information on this year's flu situation. If you are exposed to a known case of flu or come down with flu-like symptoms call your primary care physician or our nurse coordinator immediately for flu medication: it only works if started within 3 days!



REMINDER:
TIMELY VISITS = TIMELY CARE!
PLEASE BE ON TIME FOR YOUR CLINIC VISITS, AND IF YOU'RE UNABLE TO MAKE A SCHEDULED VISIT PLEASE CALL US ASAP! ANOTHER PATIENT CAN USE YOUR CLINIC TIME AND IT HELPS US RUN A MORE EFFICIENT CLINIC!

ENZYME REMINDER

Remember to check your enzyme prescription to ensure receipt of the correct enzymes! Prescriptions should state “DAW” or “Dispense as Written” to prevent generic substitutions. Generic formulations are not as effective. treatment failures and adverse reactions have been reported. Please advise us if you are having trouble with insurance authorization for brand-name enzymes.



Brands are printed on each pill: Creon, Pancrease, Pancrearb and Ultrase.

NACFC Highlights



Francis Collins, MD, PhD

Stanford sent a large contingent to the annual North American Cystic Fibrosis Conference (NACFC) in October. This year's conference hosted 3,000+ with dozens of sessions on research and clinical care. Francis Collins, MD, PhD, Director of the NIH Human Genome Project and co-discoverer of the CF gene, delivered the keynote address on the CFF's research Master Plan for genomics and drug discovery.

Major conference themes were genomics, clinical research, drug discovery, and clinical care quality improvement. Our CF team assembles each year to discuss implications for treatment and research, and share the most interesting findings.

Genomics and proteomics, and their relationship to drug discovery, dominated the research forums. New discoveries and research progress across the spectrum of basic and clinical research was presented, including work on modifier genes, high throughput screening (HTS) of chemical compounds, new antibiotics and new treatment devices. Dr. Collins predicted that the mapping of the entire human genome soon will enable identification of all the major modifier genes that effect persons with CF. HTS, a major CFF initiative, has identified several promising compounds that have advanced understanding of CF. Presentations on the new clinical quality improvement initiatives demonstrated the value of aggressive care management and the importance of maintaining health and lung function at the earliest ages. Center Director Richard

Moss closed the meeting on an upbeat presentation entitled "Disease Progression in CF: Can We Gain the Upper Hand?" He outlined current research that promises significant advances in the near future. Keynote speeches can be viewed at the CFF website: www.cff.org. Our Annual CF Education Day on March 6 will feature some of the best speakers at the NACFC conference. Other highlights include:

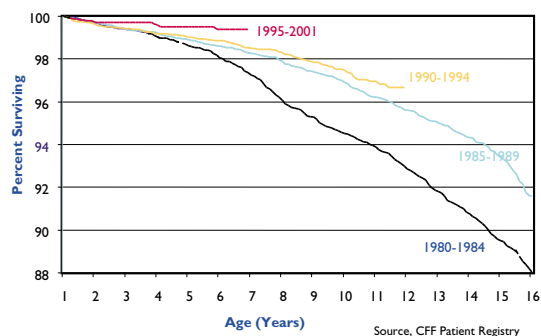
No Tipping for Infant CPT

A 5-year controlled study of standard chest physical therapy (CPT) versus modified CPT without head-down tilt (MPT) found significantly better outcomes with the modified method. Infants receiving MPT experienced fewer respiratory complications, particularly if they had gastroesophageal reflux. MPT subjects experienced fewer days with upper respiratory tract symptoms and shorter courses of antibiotics, and had better chest x-ray scores at age 2.5 years and better pulmonary function at 5 years.

Treatment Studies

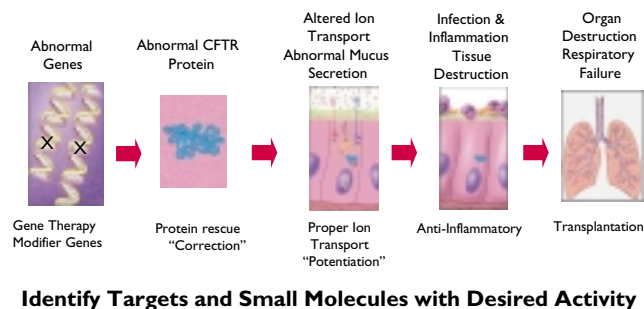
Several studies on antibiotic usage provided support to clinical protocols frequently practiced by CFF centers. The Once Daily versus Three Times Daily Tobramycin Trial, a large trial with many Stanford participants, found positive results for the once daily dosing regimen with no increase in adverse side effects. Another study found value in higher doses of ceftazadime than have generally been prescribed for some adults with CF. Several new drug delivery devices were presented that significantly reduced treatment times and improved drug deposition in the lungs. An observational study of inhaled steroids (e.g. Advair and Flovent) found a significant reduction in the rate of lung function decline following initiation of inhaled corticosteroids. Studies such as these are important to advance the effectiveness of treatment, to gain insurance coverage and to enhance quality of life.

Survival From Age One, by Birth Cohort



Source: CFF Patient Registry

Therapeutic Approaches to CF



Source: Cystic Fibrosis Foundation



SATURDAY MARCH 6: 2004 CF EDUCATION DAY

9 am to 3 pm

LUCILE PACKARD CHILDREN'S
HOSPITAL AT STANFORD

BRYAN LASK, Professor, Child & Adolescent Psychiatry, St. George's Medical School, "CF Psychosocial Issues"

WALTER ROBINSON, Associate Professor, Pediatric Pulmonary, Associate Director of Medical Ethics, Harvard, "Palliative Care"

RANDAH WHITNEY, Physical Therapist, University of North Carolina, "Exercise as Airway Clearance"

RICHARD MOSS, "Disease Progression in CF: Can We Gain the Upper Hand"

JACQUELINE FRIDGE, "Using Acid-blocking Medicines in CF—Is There a Downside?"

JOANNE ASANO, LCSW, "Parent Mentoring: the CF Warm Line"

CAROL CONRAD, "New Study on Glutathione and Inflammation in CF"

TERRY ROBINSON, "Controlled Ventilation in CF"

Panel Discussion: Transition to Independence: Strategies for a Successful Life with CF

CALL 650-723-5230 ASAP TO REGISTER

There is no cost, however registration is required. Continental breakfast at 8:30, and a catered lunch will be served.

INFECTION CONTROL: All persons with CF must wear a mask at the conference. Persons who have cultured Methicillin Resistant Staph Aureus (MRSA), Burkholderia Cepacia, or who currently culture any bacteria resistant to all antibiotics should not attend. If you have questions about your culture status, please call and ask us to check when you register. Your cooperation is appreciated in making this a safe conference for all attendees!

Stanford CF in the News

Noreen Henig will speak in March to the New Jersey Thoracic Society on Recognition and Management of Adult CF. **Richard Moss** has 2 papers in press: in *Chest* on the AAV Phase II study "Repeated AAV2 Aerosol-mediated CFTR Gene Transfer to the Lungs of Patients with CF" and in *Clinical and Experimental Immunology* "Lymphocytes in CF Lung Disease: A Tale of Two Immunities". **Terry Robinson** is organizing a meeting at Stanford in February on CT imaging in infants with Alan Brody, Bob Castile, Fred Long and LPCH physicians **Carol Conrad**, Richard Barth and William Northway.

New Osteoporosis Study

Osteoporosis or thin bones is common in CF and can be associated with fractures, including painful rib or vertebral fractures that occur just as the result of coughing. **Noreen Henig**, Adult Center Director, and **Laura Bachrach, MD**, Professor of Endocrinology are launching an investigation of a new treatment for CF-related osteoporosis to evaluate the efficacy of the FDA-approved drug teriparatide (Forteo), a drug recognized to improve bone density and restore the normal structure of bone and reduce the risk of fractures. To learn more, contact the CF Research Team or Dr. Henig.

Current Research Studies

To bring one CF drug to the pharmacy can take 8 to 10 years, \$125 million, and thousands of study participants. Nationally, 6.5% of persons with CF participate in a clinical trial compared to only 4.5% at Stanford in 2002. We'd want to exceed the national median! More participants, mean more drugs can be tested and research advanced. For information on how to participate visit www.cfcenter.stanford.edu or contact our research coordinators.

- Phase IIB gene therapy
- BILL study (ages 6 and over)
- CF.Doc internet-based clinical care (up to age 21)
- Infant and toddler pulmonary testing (4 months to 2 years)
- Concentrated TOBI (under the age of 6)
- Topical aminoglycosides
- Nasal Membrane Potential Difference
- CF Diabetes
- Aztreonam for inhalation



Adult Inpatient Staff Changes



Adult Inpatient Staff Changes

Susan Nekimken, RN, MPA has joined Stanford Hospital as manager of the Adult CF Unit, following 21 years with Kaiser. Susan looks forward to helping staff implement new programs to improve care, and views her role as "acknowledging how hard the staff work, and enabling them to achieve their goals".

Michele Culberson BSRN has transitioned to case manager and discharge planner for adult CF patients. Michele will be arranging post-hospitalization IV and home care services and working with insurers on length of stay and case management. She knows many CF patients from her 27 years as a staff nurse on Units D and E, and looks forward to assisting them in case management.



Families Living Well with CF

LPCH sponsored a 2-day workshop on "Families Living Well with CF", facilitated by Ann Robinson, parent of an adult with CF and Isabel Stenzel Byrnes, social worker with CF. Participants learned skills to manage CF, work with the health care team and help children learn healthy eating, communications skills, and adherence techniques. Contact Joanne Asano if you are interested in future sessions.

New "Warm Line" Supports CF Community

LPCH's CF Parent Advisory Group and Family-Centered Care (FCC) Program are initiating a "CF Warm Line" to provide psychosocial to CF families. FCC recognizes the family's pivotal role in care delivery and strives to support them by promoting partnerships with professionals to ensure excellence at all levels of care. A team of CF parents has been trained as mentors. Joanne Asano states, "the Warm Line provides a new dimension of support to the CF community by connecting people who seek a caring, empathetic support network with experienced parents". The "Warm Line" can be accessed by calling Joanne.

**CREON SCHOLARSHIP APPLICATIONS AVAILABLE:
SEE JOANNE ASANO FOR DETAILS**

Call for Art

The Breathing Room and CFRI are seeking artwork by adults and children with CF, family and caregivers for an exhibit entitled "One Day at a Time: Living with CF". The exhibit will be at the 2004 CFRI Conference on August 6-7 at the Sofitel Hotel, in Redwood Shores. For an application (due May 1) visit www.thebreathingroom.org or contact Catharine Martinet 818-556-3970.

CYSTIC FIBROSIS CENTER AT STANFORD

Center Physicians: Richard Moss, Director; Noreen Henig, Adult Center Director; Carol Conrad, Terry Robinson, Lauren Witcoff, Hugh Harris, Nanci Yuan

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Clinic Fax	650-497-8837
Katherine Boyle, RN Pediatric Coordinator	650-736-1359
Mary Helmers, RN Adult Coordinator	650-736-1358
Kristin Shelton, Respiratory Coordinator	650-724-0206
Violet Hsieh, Nutritionist, Dietitian	650-736-2128
Joanne Asano, Social Work	650-736-1905
Research Coordinators	650-736-0388

For Urgent Issues:

Monday-Friday 8:30-5:00 pm contact RN Coordinator
All Other Times (ask for Pulmonary Physician On-Call)
650-497-8000

See our website at <http://cfcenter.stanford.edu> for more information about our center, CF and current topics.

To subscribe to this newsletter please call or email Judy Kirby at 650-724-3474 or jkirby@stanford.edu

We gratefully acknowledge the leadership of friend and parent Penny Stroud in producing this publication.



Lucile Packard Children's Hospital

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