To Ian Klein

Windhorse Communications

Writing and Editing Services

October 8, 1998

Katharin M. Button
Assistant to the Chief of Staff to the First Lady
100 Old Executive Office Building (OEOB)
Washington, D.C. 20501

PHOTOCOPY
HRC HANDWRITING

Hello Ms. Button –

Enclosed is a package for Mrs. Clinton. It's connected with the first ever U.S. National Cystic Fibrosis Awareness Week, which starts October 11, 1998.

We'd *very much appreciate* if you could forward this to Mrs. Clinton at the earliest possible time so that she can make use of the information and contents during this special week.

Many, many thanks!

Lecia & Peter Papadopoulos

Lenora & Garry Degen

1085 Keith Drive, Colorado Springs, CO 80916 ▪ voice 719.638.0622 ▪ fax 719.638.0630 ▪ windhorse@worldnet.att.net

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Hillary Rodham Clinton
c/o Katharin M. Button
Assistant to the Chief of Staff to the First Lady
100 Old Executive Office Building (OEOB)
Washington, D.C. 20501

Hello Mrs. Clinton –

You may have heard that the week of October 11, 1998 will be the first ever National Cystic Fibrosis Awareness Week (a press release is enclosed). You've been such a strong and generous supporter in the fight to provide children with the best medical care and education possible – we want to be sure you know about this event. As parents of children with cystic fibrosis, we also want to thank you personally for your effort and concern on our babies' behalf.

We've enclosed a bouquet of Hershey Kiss roses, symbolic of the 65 Roses "nickname" that a young child innocently and beautifully gave this ugly disease. We would appreciate it if you could share these roses – and your knowledge about children and CF – with your personal and extended communities during our National Cystic Fibrosis Awareness Week. We greatly appreciate your involvement.

We've also enclosed a photograph of our beloved Lily, who turned one year old at the end of June. Lily has had a difficult fifteen and a half months – from failure to thrive, which led to her diagnosis at four months, to supplemental feeding via NG and G tube, to her first pulmonary exacerbation in July. Significant oral aversion and sensitivity, which have interfered with the development of self-feeding skills and resulted from the tube feedings, will require speech and occupational therapy to overcome. Her friend, Phillip Degen, was born with meconium ileus, and underwent immediate surgery followed by a prolonged hospital stay. Today, he requires only the basic treatments, which he tolerates well for a two year old.

But in spite of the medical interventions their bodies have needed, Phip's and Lily's spirits are strong and bright and full of joy. We are incredibly blessed to know them, and it is a privilege beyond measure to be their parents.

Thanks very much!

Lecia & Peter Papadopoulos

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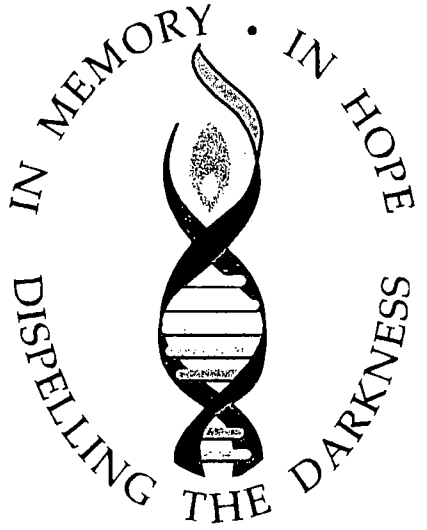

FOR IMMEDIATE RELEASE:
19 September 1998

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NATIONAL CYSTIC FIBROSIS AWARENESS COMMITTEE (NCFAC) ANNOUNCES PLANS FOR A NATIONAL CYSTIC FIBROSIS AWARENESS WEEK : OCTOBER 11-17, 1998.

From Arizona to Florida, Colorado to New York, communities across America are planning special events during the week of October 11-17.
They hope to raise awareness about cystic fibrosis (CF) and what it means to live with America's most common life-shortening genetic disease.

*** What is CF? * Who has it? ***
*** What if I am the friend, spouse or relative of a person with CF? ***
*** What if I have it? * Why do people with CF cough so much? ***
*** Can I "catch" it? * What does it do to the body? * Am I or my family at risk? * Is there a cure? * What should I know about CF? ***
*** How can I help? ***

People can get answers to these questions and more at any of the various events being held during National Cystic Fibrosis Awareness Week.

From support group meetings with guest speakers and classroom presentations to TV news special reports and handmade crafts offered through local businesses, people with cystic fibrosis and their families intend to get the word out.

THE NATIONAL CYSTIC FIBROSIS
ncfac
AWARENESS COMMITTEE

Did You Know?

- ***Cystic fibrosis is a chronic, life-shortening genetic disease. The most common one in America.***
- ***Children have it.***
- ***Adults have it.***
- ***CF is not contagious. You must be born with two CF genes in order to have CF.***
- ***Many Americans (an estimated 1 in 29) have one CF gene, which makes them symptomless "carriers."***
- ***If two "carriers" have children, there is a one-in-four chance during each pregnancy that the baby may be born with CF.***
- ***Of every 2000 births in the U.S., 1 baby will have CF. Usually it will be a terrible and devastating surprise to the parents.***
- ***Early diagnosis is important in treating CF. Only two states require neonatal or newborn screening for CF: Colorado and Wisconsin.***
- ***The "sweat test" has been the standard diagnostic tool for CF for more than four decades. It is a painless test.***
- ***The genetic defect that causes CF was identified in 1989, making it possible now to test for many of the genetic mutations that cause CF.***
- ***People with CF cough a lot, but they cannot "give" you CF. And they probably cannot give you anything else, since the "bugs" that bother CF people are common in our everyday environment and generally easy for people without CF to deal with.***
- ***People with CF have trouble gaining and keeping weight on. This is not as good as it sounds.***
- ***People with CF – like other people with chronic, system-wide conditions – have a lot of work to do to stay healthy. Typical treatments include enzyme therapy with meals and snacks, inhaled nebulizer treatments from one to several times daily, chest percussive therapy from one to several times daily, and regular or frequent oral or IV antibiotics.***
- ***Many people with CF also have diabetes and must perform those treatments at home as well.***
- ***People with CF develop other problems such as CF-related arthritis, which causes mild to severe joint pain.***
- ***When people with CF do catch even a common respiratory cold, it can take them much longer to recover. Please think twice before you go out in public, or send your child to school, with a cold.***
- ***People with CF do not have mental, emotional or visible physical impairments as a result of CF.***
- ***People with CF typically do well in school and hold productive jobs. Some people with CF are able to have families and are loving parents.***
- ***People with CF look like anybody else. You cannot "see" CF.***
- ***People with CF do not "outgrow" CF. It does not "go away" with age.***

- ***CF is a progressive and eventually fatal disease.***
- ***CF affects many organs in the body especially the lungs and pancreas, and often the liver, spleen, gallbladder, sinuses, bowels, bones, and sweat glands.***
- ***People with CF may qualify for and require special privileges, such as handicapped parking, even though they may seem young and not use a wheelchair or other assistance.***
- ***You may already know someone with CF.***

While there is no cure for CF, researchers are getting closer every day. Today, the average life expectancy for someone with CF is 31 years. Only twenty years ago it was 18. Thirty years ago, just 1968, people with CF often died as children. There has been a lot of progress in CF research and treatment in the last thirty years. We want it to continue.

Each of us can help in this effort. Participate in this year's National Cystic Fibrosis Awareness Week. Visit our website at www.inxpress.net/~paisans/NCFAC.

For more information about CF and research efforts currently underway, or to find out about volunteer and charitable opportunities, contact the Cystic Fibrosis Foundation at 800/FIGHT-CF (1/800-344-4823) or online at www.cff.org.

About the National Cystic Fibrosis Awareness Committee (NCFAC)

April Harris is 15 years old. She resides in Englewood, FL, and lives life as any other American teenager. She's optimistic, idealistic, and outgoing. She's also in the process of being evaluated for a lung transplant. April was born with cystic fibrosis.

In August 1998, April asked, "Why doesn't cystic fibrosis have a national day, like so many other causes?"

No one had an answer. The NCFAC was formed to provide that answer.

Today, the NCFAC is a nonprofit grassroots organization whose informal membership is nationwide, with ties to Australia, Germany, England, France, Holland, South Africa, South America, and India – everywhere there are people with cystic fibrosis.

The NCFAC's mission is simple and personal: to raise awareness in this country about the disease called cystic fibrosis. By raising awareness the committee members hope to accomplish three things:

- Educate the public about CF, and thereby
- Support those who live with CF, helping to improve the quality of their lives through improving the public's understanding of their disease; and,
- Support the fundraising efforts of other CF organizations, including the Cystic Fibrosis Foundation (www.cff.org). *The NCFAC is specifically not a fundraising organization.*

Among the Committee's first objectives is official recognition of an annual National Cystic Fibrosis Awareness Week each October. A letter-writing campaign is currently underway, directed to the President of the United States. Petitions and other mechanisms are under development.

NCFAC Executive Committee Members

Co-Chair Lenora Degen – Colorado Springs, CO

Mother of two boys, Alex (8) and Phillip (2). Phillip was born with CF. Lenora works part time as a graphic designer. Her reason for supporting the NCFAC's efforts: "Awareness and education are important to me. When Phillip was diagnosed, I needed personal support that I just couldn't find. There were no CF support groups in the state of Colorado, so I had to obtain the help I needed elsewhere. Eventually I became involved with email support groups and fundraising. I wrote articles and helped found our local in-person support group. I hope that through the efforts of the NCFAC other parents of newly diagnosed children with CF won't have the lonely, difficult struggle I did."

Co-Chair Mary Lou McDowell – Sikeston, Missouri

Mother of two girls, Melissa (16) and Rachel (13). Melissa was born with CF. Mary Lou is a full-time mom after having worked as a legal secretary. You could also say she's a full-time volunteer, having served the community in many capacities including: Member of the Citizens' Advisory Committee to the School Board; PTO Secretary; Church Board Secretary; Girl Scout Leader; and Sunday School teacher. "I became involved with the NCFAC because I finally saw an opportunity to make a difference in the life of my daughter. I believe that increased awareness will result in a better quality of life for her and for others with CF."

Other Executive Committee Members

Sandra Angell Buxton, Co-Chair of the Educational/Outreach Sub-Committee – Madison, Wisconsin

Mother to Samuel (10 mos), born with CF. Sandra works in the pediatrics department of Dean Clinics in Madison. Her background is in communicative disorders and special education.

Ami Chester – Fresno, California

A 19-year-old college student majoring in Child Psychology, with interest in Genetics, Amy's goals are to earn a Ph.D. and work with chronically and terminally ill children. Ami was born with CF.

April Harris – Englewood, Florida

A 15-year-old high school student who writes and publishes poetry, April has been a cheerleader, holds a GPA of 3.13, and is no stranger to academic and peer awards. Her career goals remain undecided between pulmonology and journalism. April has CF and diabetes.

Melissa McDowell – Sikeston, Missouri

A 16-year-old junior in high school, Melissa has a GPA of 3.87, and is in the top ten percent of her class. She's been honored at the district and state levels of the Missouri Junior Academy of Science and is currently working on her Girl Scout Gold Award. She's looking forward to a career as an accountant. Melissa was born with CF.

Bianca Mothe – Madison, Wisconsin
Originally from Brazil, Bianca is currently a Ph.D. candidate with the Department of Pathology and Surgery at the University of Wisconsin at Madison. She plans on pursuing a medical degree and pursuing research in the CF field. Bianca was born with CF.

Kim Payne, Co-Chair of the Educational/Outreach Sub-Committee – Stillwater, Oklahoma
Mother of two children, Brian (19) and Amanda (15 and a half). Brian was born with CF. Kim works as a writer, resource educator and consultant specializing in health issues in schools. Her many accomplishments and involvements include: a B.S. in Elementary Education; Peer Counselor Grief/Crisis Intervention; professional experience teaching severely emotionally disturbed children K-3; and development of integrated classroom lessons that link local school children to people with CF via the Internet.