



BREATHE EASY

New Jersey State Organization of Cystic Fibrosis

Established in 1977

"We are the ones who help them breathe easier"



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Our Mission

To help ease the heavy financial burden placed on CF patients and their families and to provide needed information. No other cystic fibrosis organization in New Jersey offers the same type of focused financial assistance and emotional support.

Our Motto

We help them breathe easier!

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Dick Quinn

"Stages of Life"

Ever since I can remember Estelle Sikkema, founder of the New Jersey State Organization of Cystic Fibrosis, has been part of my life. And now Debra Sikkema, Executive Director, has taken her place.

I'm 60 years old now, I live with my wife and our daughter who just started college, and I recently underwent lung transplantation. But I still reflect

back to when I was four or five years old my parents took me to the annual Christmas parties Estelle coordinated for all the children with CF. There was always plenty of food and treats, clowns and balloons, and lots of toys.

Back in the mid-1960's the NY Yankees hosted the CF organization's annual trip for the kids to Yankee Stadium. I got a baseball bat signed by Yankee greats Yogi Berra, Elston Howard and Whitey Ford! My picture was taken with Yankee pitcher Jim Bouton, and he autographed a ball for me. That's me to the right of Jim Bouton behind home plate at Yankee Stadium circa 1965. I was even in the newspapers! Then magic happened, and I had the thrill of my life when Mickey Mantle hit a home run at one of the games! As a young Yankee fan these were great moments.

But most of all Estelle and the CF organization were there for my parents when I entered high school and we needed help. NJSOCF helped my parents with their copayments for medications

and treatment, assisted them with CF medical equipment, and most importantly helped them navigate life with a young child with CF.

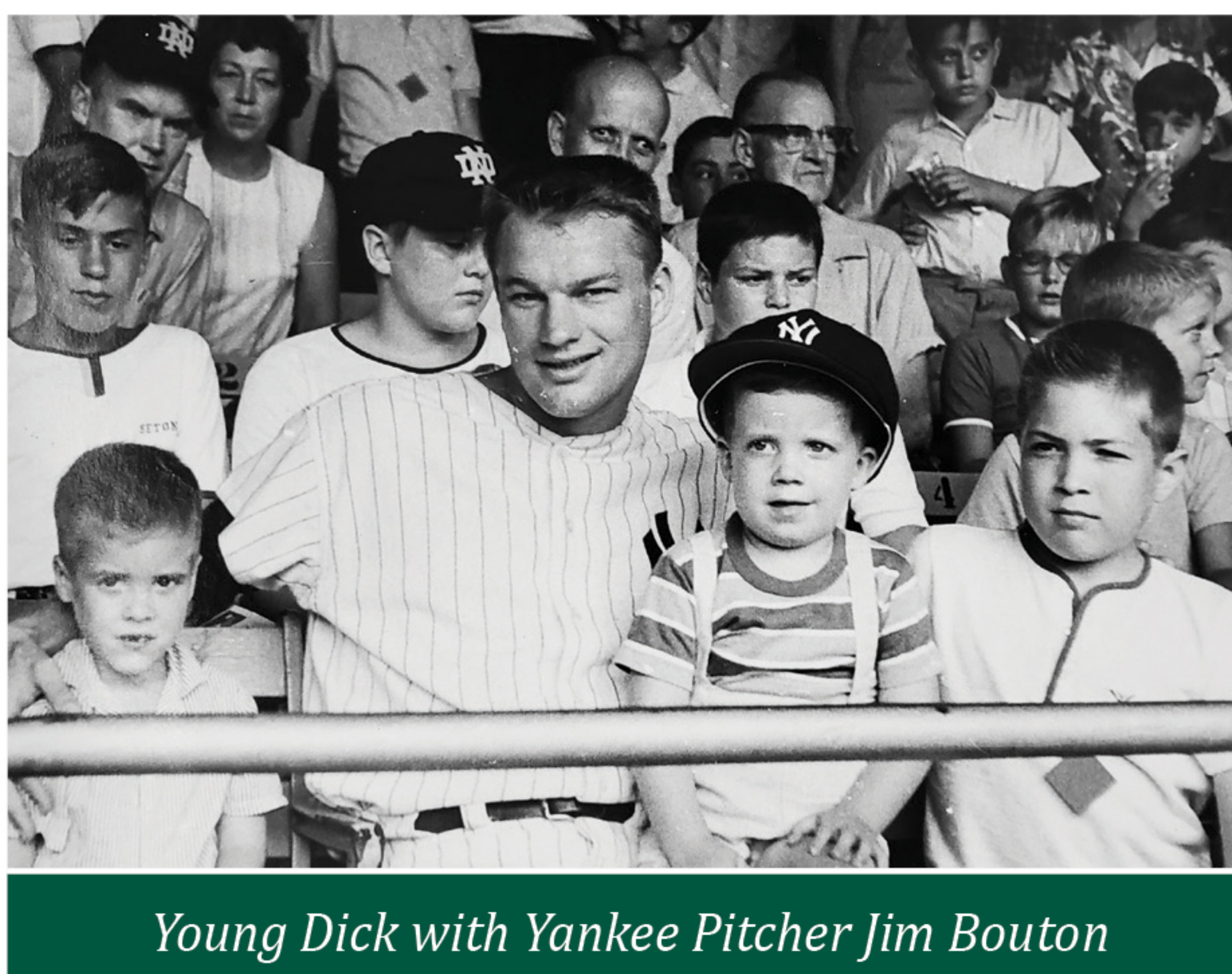
As a young adult I remember visiting the office to bring raffle books we sold for various events, and picking up the new (at the time) hand held percussor. I was told that the first percussor, designed to replace manual

chest clapping, was developed from an ordinary Black and Decker jigsaw by replacing the saw end with a cup! My Dad transitioned me to a percussor so I could be independent by doing my treatments on my own. They had a tendency to wear out but NJSOCF always had percussors available when we needed them.

Like most 20-year olds in New Jersey I spent my summers at the Jersey Shore partying with 20 of my best friends. Unexpectedly, one night I even met the Boss, Bruce Springsteen, at a bar in Belmar when he just dropped in and sang with a local band. Life was good!

At that time I had several sales jobs selling local advertising, I even had my own business for a while, but switching jobs frequently left me without health insurance for periods of up to six months at a time. But I was never without help and NJSOCF covered those large copays for me.

Then in the summer of 1989 I met Karen, my wife of 29 years. We were married after 3

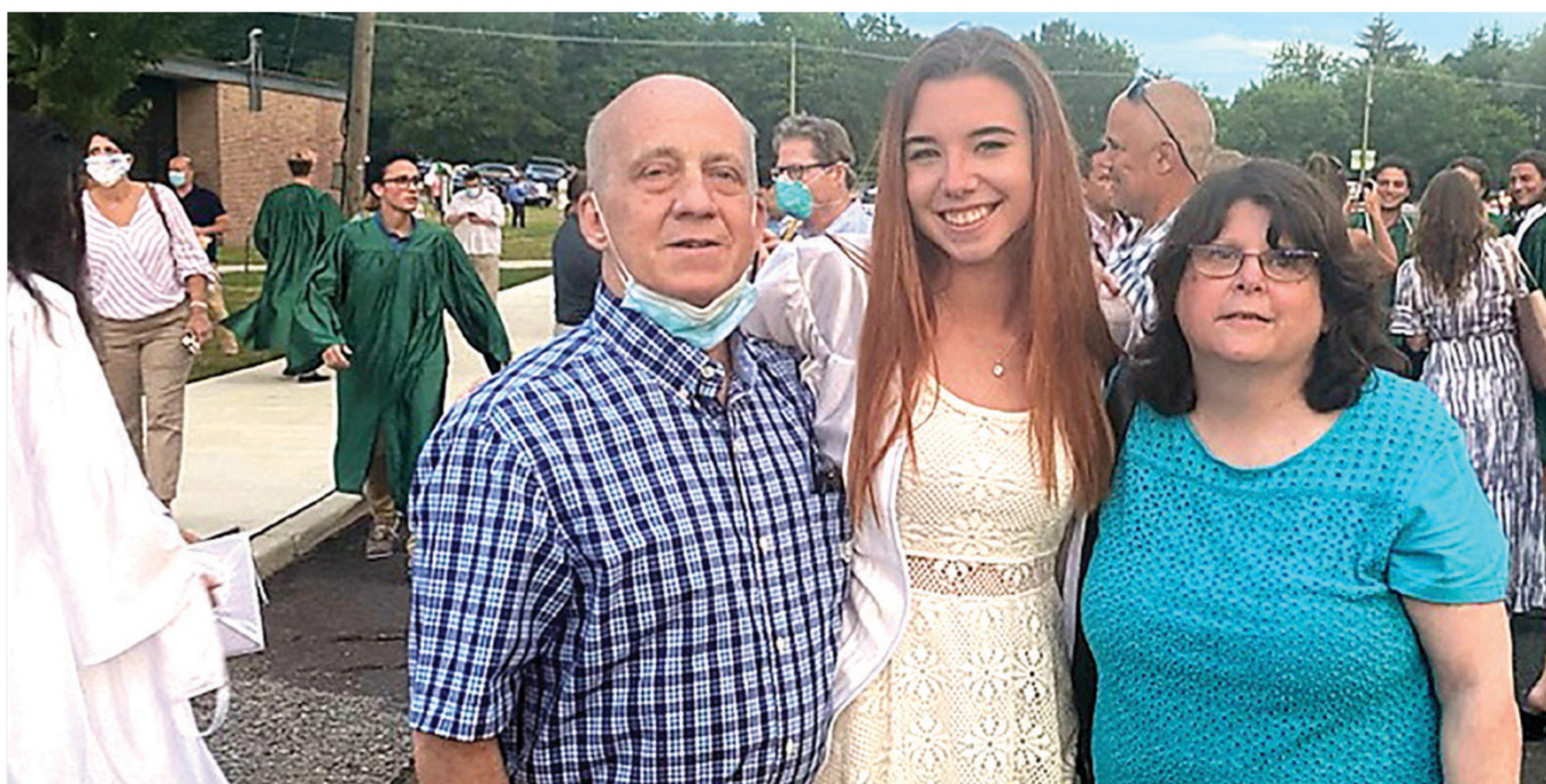


Young Dick with Yankee Pitcher Jim Bouton

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Continued from Page 1



Dick and Karen with Katherine at HS graduation

years of dating and eventually settled down in Kinnelon, New Jersey. In 2002 our beautiful daughter Katherine came into our lives. We were working, living life, and raising Katherine. I was coaching her softball team, and as a Trustee of our community we were involved in and enjoyed all the activities a lake community had to offer.

It was in 2010 that my health began to decline. That same year the company I worked for and had been top salesman for 19 years closed. I was at a turning point in my life. I always remembered what Amy, the Social Worker at St. Vincent's Hospital in New York once told me, "CF is going to be a full time job to maintain your health." A few years later, in 2012, it became evident that I needed to slow down and take care of myself. By stopping work and listening to my doctors and my body, I would extend my life, so I retired on Social Security Disability to concentrate on my health.

In the next stage of my life NJSOCF played its most important role and was the biggest help to me and my family. During the two years before my lung transplant, I was going into the hospital once a month. After those hospital stays I would be sent home to do a week or two of IV antibiotics. It was very stressful trying to coordinate nursing visits, delivery of the IV antibiotics and getting the IVs started. NJSOCF was right there to help out again and they paid those large copays on the antibiotic treatments. I was able to concentrate on my IV therapy and not have to worry about the bills coming in each month.

Karen and I just finished a four state vacation in the Midwest. Our goal is to visit all 50 states, and after this trip I'm at 41 states and Karen is at 37 states. It was wonderful to be able to kayak on Lake Superior and watch the sunrise, and to hike up to a waterfall and watch the water tumbling down 200 feet into a beautiful deep pool of water that's almost inviting you to take dip into. We watched the sunset over Iowa farms with the colors changing every couple of minutes, and hoping that it would last for hours not just minutes. Three years ago I never thought I would be able to do a trip like this again. With my lung transplant in 2019, and all the good work my doctors did along with support of the NJSOCF, I was able to take this amazing trip. God willing Karen and I will be able to reach our goal and get to all 50 states.



Dick holding a Rainbow Trout at Lake Superior

Office Chit Chat...

This year marks a milestone for a special person, our very own Bernice DeMeritt, who has given the past 25 years to NJSOCF. Her work has a very special meaning to her. "Every day when I come into work at NJSOCF I am doing it in my son Brian Moser's memory," says Bernice. "There is a purpose to my being here—to help the organization after all they did for our family during his long battle with CF."

CONGRATULATIONS BERNICE!!!!



Bernice with her son Kris, daughter in-law Jennifer and Grandchildren



In spite of another COVID year prohibiting our indoor fundraisers, including our famous "Pocketbook Bingos" which are heavily attended, NJSOCF managed to have a busy and productive year.

In May we celebrated Mothers' Day with a very successful "Make Believe" Mothers' Day Tea Party mailing campaign. This year we drew a name from our contributors to win a beautiful Coach handbag!

Sweeney & Harkin made another significant donation to NJSOCF from their annual Golf Tournament this spring and the Lindsey Meyer Memorial Foundation once again gave their support to assist and help the CF Community in New Jersey.

Thank you to all of our supporters! Looking forward to 2022!!!!

38th Annual Cystic Fibrosis Golf Tournament

Wild Turkey Golf Club



Friday, July 30 brought together friends and supporters of the annual Cystic Fibrosis Golf Tournament at Crystal Springs in Hamburg, New Jersey.

This year marked our 38th golf tournament and mother nature gave us another beautiful day. Participants enjoyed a BBQ lunch, a round

of golf at Wild Turkey Golf Course, cocktail hour and awards dinner under a tent at the beautiful Crystal Springs resort.

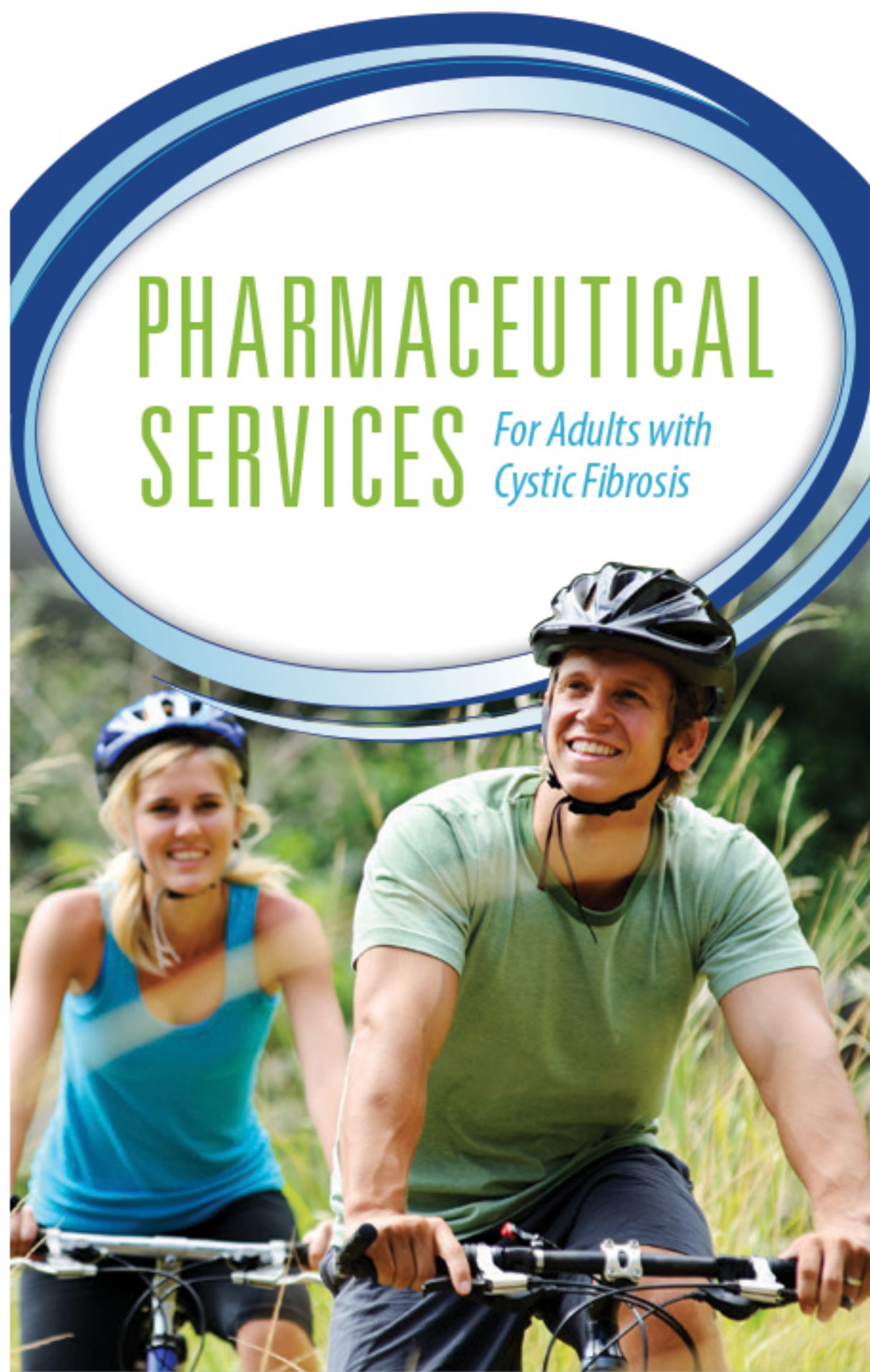
We take this opportunity to thank our hard working committee, our loyal supporters, devoted volunteers and our special sponsors, V.A.L. Floors; Konica Minolta; SBF Construction, Inc.; AEGIS Advisory Partners; Ernst & Young; Ally Construction Services; NJ Realty; Mercury; Sweeney & Harkin; RMG, CPA, LLC; and all the other sponsors and golfers who contributed to a successful event!

Thank you!



The "Adult Program" Provides Help With...

The New Jersey State Organization of Cystic Fibrosis provides assistance to individuals with CF and their families. A special program for adults over 18 helps those with CF who are out on their own living independently.



Prescription Drugs and Copays

With a doctor's prescription, the program reimburses patients for prescription medications and copayments for medications related to the treatment of Cystic Fibrosis

Office Visit Copays and Diagnostics

The program will reimburse copayments for CF-related doctor visits, including mental health visits. Patients can also be reimbursed copayments

for diagnostic testing, routine lab work, scans and x-rays related to the treatment of cystic fibrosis.

Medical Equipment and Supplies

Patients on the program can receive help paying for home care equipment and medical supplies needed to treat CF. Items include breathing equipment such as nebulizers, and home IVs. Equipment and supplies must be prescribed by your doctors, and payment authorized by NJSOCF.

Nutritional Supplements

The program can provide reimbursement for a variety of nutritional supplements, including vitamins, and prepared supplements such as Boost, Ensure and Scandishake.

Extra Nutritious Foods

Funds are available to patients to help defray the cost of the extra nutritious food they need to stay healthy.

Reimbursement for annual insurance deductible

The program will reimburse up to \$1,000 per year for your annual insurance deductible.



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That's it! It's a small step that can make a **BIG** difference!

New Jersey State Organization of Cystic Fibrosis

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Office Mascot Sunny dresses business casual.

HOW TO DONATE

ON-LINE: Making a donation on line is simple and convenient. Just visit our website—njsocf.org.

MEMORIAL GIFTS: A memorial gift to NJSOCF makes a lasting tribute to a departed loved one. A special occasion gift can be used to celebrate birthdays, anniversaries, and even be given in lieu of wedding favors.

MATCHING GIFTS: Many medium-sized and large companies offer a matching gift program.

UNITED WAY: Employees that participate in the United Way payroll deduction program at work can designate their contributions 100% to NJSOCF.