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Dave offered advice to his fellow CF patients. "Half the battle is just getting up and going to a gym, but you feel like a million bucks when you leave. While there, just do

what you can do. It should be enjoyable. Tailor your workout to how you feel, day to day. Never be excessive and push yourself too hard and you will get good results over time if you stick to it."

## Grant Renewal Application Update

*Pharmaceutical Services for Adults with Cystic Fibrosis*

Pharmaceutical Services for Adults with Cystic Fibrosis begins a new grant year on July 1, 2016.

According to guidelines, participants are required to reapply each grant year. NJSOCF will be sending renewal packages to everyone currently on the program in mid-May. Renewal applications should be submitted before July 1, 2016 to avoid any interruption of services.

All expenses for the current grant year which ends on June 30, 2016, should be submitted as quickly as possible.

Please feel free to call NJSOCF at 973-595-1232 or e-mail [das@njsocf.org](mailto:das@njsocf.org) with any questions.

Our adult program includes providing help with prescription drugs and co-pays; medical equipment and supplies; nutritional supplements; and extra nutritious foods.

If you are new to our Organization you can visit our website, [njsocf.org](http://njsocf.org), to see if you meet our eligibility requirements and then download the required application package. You can also call the NJSOCF to receive an application package through the mail.

### New Jersey State Organization of Cystic Fibrosis

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### Our Mission is...

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 combined with education and counseling.

### How to Donate

#### *On-Line*

Making a donation on line is simple and convenient. Just visit our website—[njsocf.org](http://njsocf.org)—and click on "Just Give.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.

For all "In memory of" and "In honor of" donations, NJSOCF will immediately send a card to the family of the individual mentioned. The donor will receive a separate acknowledgement card mentioning the specific amount of the gift for tax purposes.

All checks should be made payable to NJSO Cystic Fibrosis.

#### *United Way*

Employees that participate in the United Way payroll deduction program at work can designate their contributions 100% to NJSOCF. If no designation is made, each contribution is divided among the many organizations the United Way helps support. If you want to make a 100% contribution to NJSOCF, fill out the forms provided by your employer.

# 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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## Dave Berkenbush: Fit for Life

Dave Berkenbush was born in 1960, back in the days when CF diagnosis and treatment was far less advanced than it is today. Not diagnosed until he was 23, Dave has fought the disorder since then, relying on a regular exercise regimen to help keep himself in good health.

"I was sick my whole life with lung infections," but it wasn't until I was in college, Northwestern University in Iowa, that my mother called me to tell me my older brother Bob had tested positive for CF. Back then, people barely knew what it was. For some reason, it never occurred to any of us that I could have it too."

Dave continued with his studies, always feeling ill, with bad coughing and daily gastrointestinal disturbances. "I was just never at my best in college because I was always sick," he said. "But I persevered and got my B.A. degree."

After graduating David finally had a CF sweat test at the age of 23 and discovered that like his brother he had CF. "At that time, age 23 was the full life expectancy for CF patients," he said. "You can imagine how I felt."

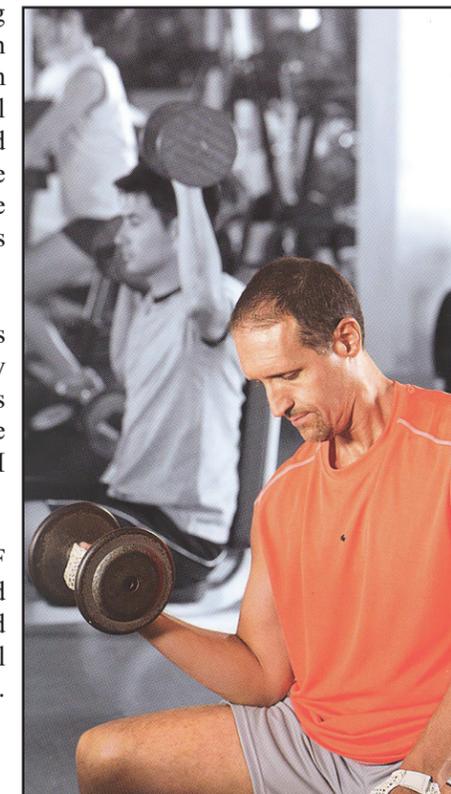
### Determination

Determined to extend his life, Dave went to several CF clinics and doctors, but they were mostly geared to children. "It wasn't until I made contact with NJSOCF and signed up for the adult program in 1990 that things started looking up," he said. "Through them I heard about a new clinic for adults in Morristown and this was something of a turning point."

Prior to going on the adult program, Dave had heard that exercise was beneficial for CF patients. "I signed up at a

Jack LaLanne gym with a friend in 1986 and went three times a week, using their machines and free weights."

Dave said he prefers working out with free weights, but after his partner could no longer come with him, he decided to switch to the machines for safety reasons.



"I still got very good results," he said. "Regular exercise definitely cuts down on the amount of CF symptoms and sickness. Exercise expels mucus from your lungs and builds up chest muscles. Your lungs function a lot better."

Dave has been sticking to his exercise regimen for almost 30 years, adding swimming at one point.

"I am now at a state of the art club, 24 Hour Fitness, at the Willowbrook Mall" in Wayne, he said. They have a huge pool with lanes for doing laps. But as luck would have it their water aerobics classes are in conflict with my schedule, keeping me from using the pool. So for now, I am using the machine weights on a three-day a week basis, Tuesday, Thursday and Saturday."

### Advice

Dave said he believes that exercise has definitely prolonged his life and prevented him from being constantly sick. "Exercise forestalls and delays the progression of CF," he said. "I love my exercise program and never want to miss a day. I attribute my being 55 to regular exercise."

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## Daily Tips: Exercise and CF

### Why Exercise?

It helps you feel better! Those who exercise do better health-wise than those who don't. Their lung function decline slows and they enjoy a more normal lifestyle. Regular exercise keeps the heart stronger and improves lung function needed to fight off infection. Exercise helps you be less limited in what you do with friends and family, increases self-esteem and gives confidence.

### What Kind of Exercise?

It is important to find an activity you like, and it should fit into your schedule. The activity should also connect you to friends or family, such as a sports team or finding an exercise partner for classes or the gym. Finally the exercise should be cardiovascular, which means it works your heart and lungs. Resistance exercises involving weights are good for helping you get stronger muscles and bones.

If exercise is new to you, then you should talk to your CF Center first. Some activities can make heart and lung disease and bone and joint problems worse.

When planning an exercise program, pick comfortable activities that you like; choose activities that work your heart and lungs the whole time; find an exercise partner to help you stick with it; do a variety of activities to reduce boredom; choose activities that fit your daily life; pick lifetime activities like running and biking; set fair yet challenging goals. Most of us won't become paid athletes but we can all improve our health!

## NJSOCF Hits the Road to Raise Awareness

NJSOCF staff and volunteers hit the road over the past months to raise awareness about cystic fibrosis and the services available through our organization.



The NJSOCF team was on hand all day

Local health fairs yielded great results, with the NJSOCF team participating in "Commit to be Fit," Totowa's Community Health and Wellness Fair, held at the Police Athletic League (PAL) in Totowa on October 17 and the Wayne Township 37<sup>th</sup> Annual Health Fair held at Wayne Valley High School on Oct. 31.

"The health fairs were a lot of fun," said NJSOCF Executive Director Debra Sikkema. "We were one of many health-related organizations that offered a variety of screenings, including blood pressure and cholesterol; safety information and

information on health resources in the local community. We set up a long table, stocked with information about our programs and collected e-mail addresses for future contact. Both days were a prime example of community networking, which we believe will be really beneficial."

Ms. Sikkema said NJSOCF has already signed up for some health fairs in 2016. "We enjoy them and it's a great way to connect to the local community."



The NJ Devils supported the Totowa Health Fair

## Special Events – Coming and Going

### Bowl \*4\* CF Awareness a "Strike" on November 7

The annual bowling event was held once again at the North Arlington Bowl-O-Drome in North Arlington.

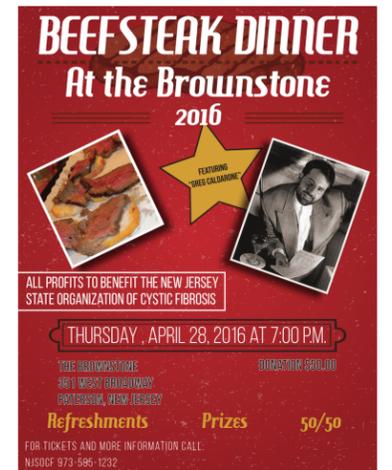


The event is two-pronged. It helps raise the level of public awareness about Cystic Fibrosis and also raises funds to support NJSOCF programs and services.

George McDermott of North Arlington did his usual outstanding job as event coordinator. Mr. McDermott is a member of the NJSOCF Board of Directors, a dispatcher for the North Arlington Police Department and an EMT. He has battled CF his entire life and is an important member of the NJSOCF team.

### Beefsteak at the Brownstone

Meat lovers had a great time indulging their taste for beefsteak with all the traditional trimmings at NJSOCF's fundraiser held Thursday, April 28 at the Brownstone in Paterson. Vocalist Greg Calderone entertained guests with a selection of old standards and new hits and guests enjoyed winning prizes and knowing their contribution would benefit patients served by NJSOCF.



### Mother's Day Tea

One of our tried and true fundraisers, the annual Mother's Day Tea is gearing up to start in May. Last year's event raised more than \$13,000 to support NJSOCF programs.

Each year our dedicated "hostesses" send out pretty invitations including tea bags provided by Wegmans to their friends and relatives. The invitations ask them to join in a "Make Believe" Mother's Day Tea Party where they stay at home, brew a cup of tea, and then make a donation of their choice to NJSOCF.

We are hoping for another big success from this year's event.



### 33<sup>rd</sup> Annual Golf Tournament

Come join us on Friday, August 5 for the big event of the year, our 33<sup>rd</sup> Annual Golf Tournament.

This year, we will be at the beautiful Ballyowen Golf Club, exclusively, so get your reservations in as soon as possible. Participation is limited!

\$250 per person includes barbecue lunch, golf, cocktail hour and dinner and awards.

### Pocketbook Bingo

Grab your girlfriends and come to the Pompton Lakes Elks Lodge on October 6 and play Bingo to win beautiful designer handbags including Coach; Michael Kors; Kate Spade and other luxury brands. The fun begins at 7 pm.

The idea is simple—just play Bingo, win, and collect your beautiful prize! Refreshments will be available from the Elks and a good time—for a good cause—is sure to be had by all.