

D A Y B O O K

PHOTO OP
WEDNESDAY, MARCH 23, 3:45 P.M.

NEIL AND JACQUELIN BURCH
"1994 MARCH OF DIMES NATIONAL AMBASSADORS"

Staff: Alec Vachon (4-8959)

Purpose: Photo w/1994 March of Dimes poster children, Neil and Jacquelin Burch (six-year old fraternal twins) from Cincinnati, Ohio. Born 3 months premature in 1987, spent first 11 weeks of life in neonatal intensive care unit. Initially had severe breathing problems -- on respirators -- and other medical problems. Today, they are healthy, vibrant. Theme: Innovative health care technology and good prenatal care made it possible for these children to survive and then thrive. MARCH OF DIMES BACKGROUNDER ATTACHED.

Who Else: Donna Burch, children's mother--also a March of Dimes volunteer.
Diane Serratore/Manager of Chapter Relations/March of Dimes.
Vivian Gabor/Senior Associate/Government Relations, March of Dimes.

Mission: March of Dimes was originally founded in 1938 by Franklin Roosevelt to eliminate polio. March of Dimes supported much of the early research on polio vaccine.

In 1958, after successful polio vaccine, March of Dimes took on new mission -- preventing infant mortality and birth defects. 75% of efforts focused on prevention, 25% on services to children with defects. Advocates for access to prenatal care; provides funding for research on genetic therapy.

Third largest national voluntary health foundation -- 100 chapters (at least one in every state); 1,000,000 volunteers, who raise \$155 million annual budget.

Wed, March 23

3:45

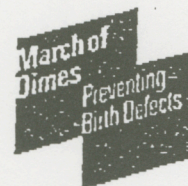
M E M O R A N D U M

TO: Senator Dole
FROM: Yvonne
DATE: March 17, 1994

-- Neil & Jacquelin Burch, six-year old tiwns, are the 1994 March of Dimes National Ambassadors, and will be in Washington next week and request a photo op with you. This is the 4th time the March of Dimes has selected a healthy child, who was born critically ill, to represent the organization. Do you want me to schedule a photo op?

yes no

March of Dimes
Birth Defects Foundation
National Office
1275 Mamaroneck Avenue
White Plains New York 10605
Telephone 914 423 7100



Contact: Vivian Gabor
Senior Associate
(202) 659-1800

BACKGROUND
1994 MARCH OF DIMES NATIONAL AMBASSADORS

NEIL AND JACQUELIN BURCH

Birthday: December 5, 1987
Parents: Alan and Donna Burch
Address: 4533 Forest Haven Lane
Cincinnati, Ohio 45103

Neil and Jacquelin's Story

On December 5, 1987, Neil and Jacquelin Burch came into this world fighting for their lives. They were born three months prematurely. Neil weighed just 1 pound, 15 ounces. Jacquelin weighed only 1 pound, 12 ounces. Today, the twins are healthy, vibrant children doing all the things that normal 6-year-olds enjoy.

Medical Background

Donna Burch found out eight weeks into her pregnancy in 1987 that she and her husband were expecting triplets due to arrive March 3, 1988. This put her into a high-risk category. She saw her doctor for monthly check-ups and ultrasound tracking of the babies' growth. But in December, one of the babies' amniotic sacs broke. Donna's doctors couldn't stop labor, so they performed an emergency Cesarean-section.

- more -

Neil, Jacquelin and Courtney Burch were born at University Hospital in Cincinnati, Ohio, on December 5. Courtney was the sickest at birth, suffering from lung problems and a heart defect that later required surgery. She died at eight months, never making it home from the hospital.

Neil and Jacquelin spent the first 11 weeks of their lives in a neonatal intensive care unit (NICU) because they were born too small, too soon. "There seemed to be more equipment than babies those first few days in the NICU," said Mrs. Burch. Respirators helped each child breathe, IV pumps delivered nourishment and medicine, and monitors to alert the NICU team to any irregular breathing or heart beats. Bright fluorescent (billiruben) lights were added to the isolettes to help their tiny bodies battle jaundice.

After three weeks, they were diagnosed with RDS (respiratory distress syndrome). Babies with RDS have immature lungs, lacking surfactant that develops naturally in full-term babies. The lungs collapse after exhalation, making the continuation of breathing difficult. About the time the twins were diagnosed, they had worked their way off the respirators, with only a few relapses back onto them. An oxygen boost and nose tube were provided for about one week before both were breathing room air. "We played a waiting game as Neil and Jacquelin passed each requirement to be sent home -- maintain body temperature, no more apnea (no breathing for more than 20 seconds) and finally hitting the elusive 5-pound plateau," said Mrs. Burch. "Eleven weeks after their birth, they came home without any monitors, oxygen or special restrictions."

The March of Dimes Role in Their Story

In the 1960s and '70s, the March of Dimes spearheaded the development of NICUs where babies born too small or very sick, like Neil and Jacquelin, would receive specialized care. The March of Dimes initiated, helped organize and contributed funds for a regional system of NICUs, making it possible for more infants at risk to be treated in technically advanced units. The Foundation also helped provide new lifesaving equipment to many of these NICUs and arranged for infants to be transported to top-level facilities.

In the 1980s, a March of Dimes grantee, T. Allen Merritt, M.D., of the University of California, San Diego, helped develop treatment for RDS, by replacing the surfactant that immature lungs lack. Surfactant, a mixture of substances with detergent properties, keeps the tiny air sacs of the lungs from collapsing after exhalation. Once surfactant reaches the lungs, it acts as a lubricant, keeping the inflated lungs open enough during exhalation so the next breath is possible. Babies struggling for breath show immediate relief after treatment and begin to breathe more easily.

When Neil, Jacquelin and Courtney were born, surfactant therapy was still in the experimental stage for the treatment of RDS, and was not available to them. "We believe if surfactant had been available when the triplets were born, Courtney would be alive today," said Mr. Burch.

During the 1980s, about 5,000 of the 50,000 babies who developed RDS each year died. Surfactant treatment, approved by the Food and Drug Administration in 1990 after Dr. Merritt and others demonstrated its effectiveness, cuts these death rates by at least a third according to study published in the July 1991 issue of *Pediatrics*.

The Role as the 1994 National Ambassadors

As the 1994 National Ambassadors, Neil and Jacquelin will travel across the country, attending March of Dimes events, meeting volunteers and appearing with celebrities and government officials to raise awareness of the March of Dimes mission.

This is the fourth time the March of Dimes has selected a healthy child, who was born critically ill, to represent the organization. **This is the first time the Foundation has named twins as its National Ambassador(s).** Neil and Jacquelin represent the thousands of miracle children across the country who are healthy as a result of March of Dimes programs and research.

Information about Neil and Jacquelin Burch

The twins attend Willowville Elementary School in Cincinnati, Ohio. They love playing with puzzles and action figures. They watch *Barney* and sing along with the songs. Neil prefers fish sticks, macaroni and cheese over Jacquelin's Popsicles and other sweets.

Information about Neil and Jacquelin's Family

Neil and Jacquelin's parents, Alan and Donna, have been volunteers for the Southwestern Ohio Chapter of the March of Dimes in Cincinnati for more than a year. They actively participate in all the chapter's events and activities, including WalkAmerica.

Alan works as a consultant for McGraw-Hill and graduated from Indiana University. Donna, also a graduate of Indiana University, is busy being a mom and housewife.

Neil and Jacquelin have one brother, Evan, who is 2-years-old.

About the March of Dimes

The March of Dimes is a national voluntary health agency whose mission is to improve the health of babies by preventing birth defects and infant mortality. Through its Campaign for Healthier Babies, the March of Dimes funds programs of research, community services, education and advocacy.

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