

SKIP of New York Timeline

SKIP Highlights



1981

- Margaret and Yves Mikol make history by bringing their 2 ½-year old daughter Julia, born with Severe Combined Immunodeficiency Disease, home from the hospital. As the first parents in New York State (and the second in the U.S.) to bring a child home on life support, they give their daughter a childhood - and reduced the cost of her healthcare by 85%.

1983

- Margaret Mikol answers calls from parents in similar situations seeking help. The Mikols establish SKIP, a 501(c)(3), to bring children home - and they advise at no cost to the families. For the first few years, SKIP operates from the Mikols' apartment.

1984

- In August, *NBC Evening News* features a story on the Mikols, their daughter and the recently launched SKIP. It is reported that care at home costs \$50,000 annually as opposed to the \$360,000 cost for long-term hospitalization.



1986

- SKIP is awarded a Federal Special Projects of Regional and National Significance (SPRANS) grant through the U.S. Department of Health & Human Services - the first such award to a grassroots family-based organization.
- SKIP moves out of the Mikols' apartment and into its first office at 990 Second Avenue.
- Julia Mikol passes away after living at home for five years with the help of a respirator.



1987

- SKIP launches its first *Turkey Trot* to provide Thanksgiving dinners for its neediest families - it becomes an annual event.

1988

- SKIP opens offices in Rochester and Buffalo to advocate for children with medical complexities.
- The first of many guides SKIP will publish is released: *Families to Families: An Introduction to the Home Care Experience*.



1989

- New York State Department of Social Services proposes the first partnership between a parent-run, community organization (SKIP) and the government. This transforms SKIP from a state advisor/advocate into a service provider/advocate.
- SKIP advocates for the *Medicaid Model Waiver*, which the NY State Legislature enacts, creating the *Care at Home Waiver*.



Related Medical & Political Milestones

1981

- Katie Beckett, five months old is hospitalized in Cedar Rapids, IA with a brain infection. Katie recovers, but needs a ventilator to breathe. Medicaid, the government health insurance program, refuses to pay for her care unless it is done in the hospital - even though treatment at home would be one-sixth the cost. President Reagan changes the Medicaid rules, and Katie goes home. She is the first child to receive a "waiver". The *Katie Beckett Waiver*, also known as the *Deeming Waiver* or the *2176 Model Waiver*, allows all disabled children to be cared for at home and receive Medicaid.



1983

- *Orphan Drug Act* passed, enabling the FDA to promote the research and marketing of drugs needed for treating rare diseases.



1984

- First U.S. law mandating seat belts is enacted in New York - saving lives and reducing the risk of disabling injuries.

1986

- Bernard Carabello founds the *Self-Advocacy Association of New York State* to assist people with disabilities.
- New York State Department of Social Service announces Federal Waivers for Home and Community Based Services - the beginning of the *Care at Home Programs* for children with medical complexities.

1988



- *Rain Man*, with Dustin Hoffman as an autistic savant, is released raising public awareness of the disorder.
- Students at Gallaudet University (est. 1864 - the only higher education institution for deaf students) protest the selection of Irving King Jordan who becomes Gallaudet's first deaf president.

- The Museum of Modern Art exhibit, *Designs for Independent Living*, features products for the elderly and those with disabilities that are both utilitarian and attractively designed.

MoMA

1989

- The gene causing Cystic Fibrosis, one of the most common genetic disorders, is discovered. Gene therapy trials for treatment begin in 1993.
- *My Left Foot* with Daniel Day Lewis is released about noted author and painter Christy Brown who had Cerebral Palsy and could only control (and work with) his left foot.
- *Mouth: The Voice of Disability Rights* begins publication in Rochester, NY.



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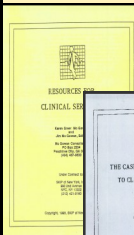
SKIP Highlights

1990

- SKIP begins providing case management services to children in Buffalo and Rochester through the *Care at Home Program*.

1991

- To help families understand complex medical terms, SKIP produces the *Quick Reference Guide* to provide clear definitions.



1992

- SKIP continues to expand its series of resource guides with *Financial Guide for Families*; *Come Together: The Experience of Families of Children with Severe Disabilities or Chronic Illness*; and *The Cost of Providing Medical Care and Related Services to Children with Complex Healthcare Needs*.

1993

- New offices: SKIP moves to 545 Madison Avenue.
- SKIP starts offering *Comprehensive Medicaid Case Management Services (CMCM)* to individuals with developmental disabilities.
- Donna Andrzejewski, SKIP's Upstate Director, receives the Governor's *Decade of the Child* award for "Dedicated services to children with disabilities".
- *The Case Manager's Guide to Clinical Services and Diagnoses Resource Manual* is published by SKIP.

1994

- SKIP starts offering *Home & Community-Based Services (HCBS)* for New York's five boroughs in April.
- SKIP launches its *Early Intervention Program (EI)* to coordinate treatment for developmental delays in children 0-3 years of age.

1995

- To provide Christmas for its most disadvantaged families, SKIP partners with RFR Realty and collects truckloads of toys and new clothing for thousands of SKIP children—and their siblings.

RFR

1997

- Tenth anniversary of the *SKIP Turkey Trot* – hundreds of turkeys were distributed for Thanksgiving over the past decade.



1999

- On December 31st SKIP New York moves to larger offices at 213 West 35th Street.
- SKIP opens a satellite office in Port Jefferson, LI.

2000



- Margaret Mikol becomes an Almoner for the *Havens Relief Fund Society* (est. 1871). Hundreds of SKIP families receive funds to overcome emergency financial situations.

Related Medical & Political Milestones



1990

- President Bush signs the *Americans with Disabilities Act (ADA)* mandating equal access to those with disabilities.
- *Safe Medical Devices Act* requires reporting of any medical device that causes or contributes to the death, illness, or injury of a patient. The Act authorizes FDA to order product recalls and other actions.
- Oxo International launches its *Good Grips* kitchen utensils for people with arthritis. Other companies start making specialized products for aging people and those with disabilities.



1991

- The federal government makes Autism a special education category; public schools begin identifying children on the spectrum and offering services.

1992



- The United Nations establishes *International Day of Disabled Persons* to create awareness and understanding.

1993

- In *Mavis v. Sobol*, a New York court found that a school had inadequately met a student's special needs.



1994

- *New Bicycle Helmet Law* in New York requires helmets for those under the age of 14. Each year in New York State, bicycle-related injuries result in 54 deaths and over 2,000 hospitalizations. Of these, over 38% involve a brain injury, a leading cause of death and permanent disability.
- *Forrest Gump*, about an intellectually disabled man played by Tom Hanks, wins an Oscar for Best Picture.



1995

- *The American Association of People with Disabilities* is founded in Washington, D.C.
- P.B.S. broadcasts *When Billy Broke His Head... and Other Tales of Wonder* by filmmaker Billy Golfus about disability in the U.S.

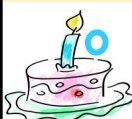


1996

- *The Telecommunications Act of 1996* mandates that services and equipment (e.g., telephones, television, computers) be "designed, developed and fabricated" to be accessible and usable to those with disabilities.

1998

- The FDA's *Pediatric Rule* requires drug manufacturers to conduct safety and efficacy studies in children.



1999

- Tenth anniversary of the *Medicaid Model Waiver* in New York State.

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2001

- Antonia C. Novello, M.D., M.P.H., Dr. P.H., New York State Commissioner of Health states: "As with any effective advocacy organization, SKIP is often demanding, but their commitment and skill is undeniable. Anyone who finds SKIP challenging would call them first, if they needed help for their child."



2002

- SKIP launches the *Ruby Slipper Award* to honor outstanding contributions to those with special needs. Meredith Vieira hosts and New York State Commissioner of Health Antonia Novello, M.D., M.P.H., Dr. P.H., is the first honoree. A large crowd gathers for the June event, held at Christie's Auction House.



2003

- Kathy Broderick and Deirdre Imus receive the *Ruby Slipper Award*.
- On May 11, SKIP sponsors the Mother's Day Half-Marathon under the aegis of New York Parks & Recreation.
- Margaret Mikol honored with the *Children's Champion Award* by *Child Magazine*.



2004

- *Ruby Slipper Honorees* are Jim & Jill Kelly and Fred Epstein, M.D.



2005

- Caroline Kennedy and Alice & David Jurist receive the *Ruby Slipper Award*.
- SKIP expands to another floor on West 35th Street.

2006

- *Ruby Slipper Awards* host Bob Shieffer honors Joel & Susan Hollander and Dana Reeve.

2007

- Caroline Kennedy hosts the *Ruby Slipper Awards* honoring Dorothy & Hamilton Jordan and Mortimer B. Zuckerman.
- Caroline Kennedy authors *RX: Home Care* about SKIP which appears in *Time Magazine* in June.
- Margaret Mikol appointed to the 16-Member *Long-Term Care Advisory Council* by the Commissioner of the New York State Department of Health.



2008

- 25th Anniversary. To date SKIP has helped thousands of children and their families.
- Margaret Mikol receives the New York State Developmental Disabilities Planning Council *2008 Achievement Award*.

Related Medical & Political Milestones

2001

- In *PGA Tour, Inc. v. Martin*, the U.S. Supreme Court rules that the *Americans with Disabilities Act* prohibits the PGA from denying Casey Martin equal access to its tours on the basis of his disability (a degenerative circulatory disorder preventing him from walking golf courses) and that allowing Martin to use a golf cart, despite the walking rule, is not a modification that would "fundamentally alter the nature" of the game.



2002

- *The Best Pharmaceuticals for Children Act* improves safety and efficacy of patented and off-patent medicines for children.

2003

- The New York State Assembly *Legislative Disabilities Awareness Day* (LDAD) is held on June 11th in Albany. The purpose is to educate legislators on important issues, to provide information on the latest services and to highlight the accomplishments of advocates and persons with disabilities.

2004

- The *Disability Pride Parade* is relaunched in Chicago on Sunday, July 18, 2004 as an annual event. The first such parade was held in Boston in 1990, but did not continue past 1991 due to the death of lead organizer, Diana Viets, and the move of co-organizer Catherine Odette to Madison, WI.

2005

- *The Schneider Family Book Awards*, which "honor an author or illustrator for a book that embodies an artistic expression of the disability experience for child and adolescent audiences", expand. Three categories of awards are now given: *Teen Book*, *Middle School Book* and *Young Children's Book*.

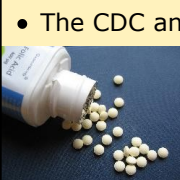


2006



- Centers for Disease Control (CDC) estimate the prevalence of Down Syndrome to be 1 in 733 live births – down from 1 in 1087 in the 1983-1990 period.

2007



- The CDC announces that the prevalence rate of Spina Bifida declined 31% to 3.49 per 10,000 children in the 1998-2006 period due to a daily dose of folic acid for women of childbearing age.

2008

- The CDC reports that about 1 in 323 children have Cerebral Palsy, the most common childhood motor disability.

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2009

- Deirdre & Don Imus present the *Ruby Slipper Award* to Phyllis & David Komansky and Bill White.

2010

- To accommodate over 300 staff members, SKIP of New York moves to the Starrett-Lehigh Building at 601 West 26th Street.
- The Buffalo and Rochester offices have grown with demands for service coordination and case management; each office now employs 24 people.
- In October, the *Medicaid Service Coordination Program* is redesigned by OPWDD. Maximum allowable caseload sizes increase from 30 to 40; SKIP maintains lower caseloads for its caseworkers in order to continue providing the highest level of service for its children and their families.
- SKIP opens a satellite office in Painted Post, expanding its reach in the Southern Tier of New York. Service coordination for both *Medicaid Service Coordination* and *Care at Home* programs is offered.



2011

- *Ruby Slipper Awardees* are Larry Inserra, Jr. and Mick Ebeling.
- SKIP and leading jeweler Carelle launch the *Home Collection of Jewelry* to benefit SKIP. The SKIP logo of a house is featured on gold and silver necklaces, earrings and charms, and are modeled by Deirdre Imus. SKIP establishes an LLC for the new venture.



carelle

2012

- Joseph & Donna Sanzari receive *Ruby Slipper Awards*.
- As demand for services increases, SKIP develops the *Needs Assessment Video* - an innovative way to fulfill the legally-mandated requirement of pre-intake analysis of children and their families. The Videos save time and money and assure efficient and accurate analysis.

2013

- The *Ruby Slipper Award* is presented to James Moran and Katie Wright.



2014

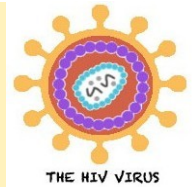
- *Ruby Slipper Awardees*: Meredith Vieira, Richard Cohen, Sally Quinn, Quinn Bradlee.
- Over 800,000 children in New York suffer from autism or other developmental disabilities, were born with birth defects or experienced disabling accidents. Today SKIP helps over 5,000 children a year—at no cost to the families. With an average wait list of 250-300 children, and government budget cuts, SKIP's need for funds remains critical.



Related Medical & Political Milestones

2009

- Pediatric AIDS: An estimated 166 children under 13 years of age are diagnosed with HIV, and 13 children are diagnosed with AIDS. This represents a major decline since 1992, when over 900 cases were reported.



2010

- *The Patient Protection and Affordable Care Act* is passed: As of 2012, insurance companies cannot put a lifetime cap on coverage; as of 2014, they cannot deny coverage based on preexisting conditions.
 - New York's Office of Mental Retardation and Developmental Disabilities, created in 1978, changes its name to the Office for People with Developmental Disabilities (OPWDD). It coordinates services for over 126,000 people directly and through a network of over 700 providers, such as SKIP.

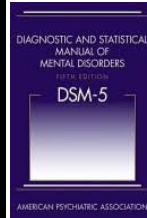


2011

- Since the *Katie Beckett Waiver* came into effect, over 500,000 families have brought their children home.

2012

- As a result of a lawsuit, Lincoln Center adds wheelchair seating, accessible parking and renovates restrooms for easier access.
- Governor Andrew Cuomo creates the *Justice Center for the Protection of People With Special Needs*, to police abuse and neglect of over one million New Yorkers with developmental disabilities, mental illnesses and other conditions. A revised state public disclosure law requires service providers to make records of abuse and neglect public.
- Katie Beckett dies at age 34.



2013

- *The Diagnostical and Statistical Manual of Mental Disorders* (DSM-5) folds all sub-categories into one umbrella diagnosis of Autism Spectrum Disorder (ASD). ASD is defined by two criteria: 1) Impaired social communication and/or interaction, and 2) Restricted and/or repetitive behaviors.

2014

- A 1,500-year-old skeleton of a child is found in eastern France; testing determines that this child had Down Syndrome, the oldest case ever confirmed.
- A class action lawsuit is filed alleging that New York State health officials denied or cut Medicaid home care services to chronically ill and disabled people without proper notice, the chance to appeal or even an explanation - all violations of law.

