Knowledge concerning those who have Down syndrome is disseminated through conferences, workshops, staff development programs, networking and outreach. The Center provides information regarding developmental disabilities to parents and families, the public, professionals and the Pathfinder Village staff in conjunction with an extended network of organizations and research facilities focusing on Down syndrome. The Center's work assists in refining the understanding of the needs of individuals who have Down syndrome, resulting in an improved quality of life for those who live at Pathfinder Village and around the world.
“...THAT EACH LIFE MAY FIND MEANING®”
THE KENNEDY•WILLIS CENTER ON DOWN SYNDROME opened its doors in 1996 as the fulfillment of a long-held dream to share the knowledge learned at Pathfinder Village with others seeking information about Down syndrome. The Center’s mission is three-fold: to present opportunities for education, to provide information and advice, and to offer resources for research studies by accredited agencies at Pathfinder Village.

Through the years the Kennedy•Willis Center has responded to thousands of inquiries worldwide from families, care providers, professionals, and organizations seeking information about Down syndrome, a chromosomal disorder which causes delays in physical and intellectual development. True to its founding goals, the Center continues to provide much-needed services to families seeking help for loved ones who have Down syndrome. This “focus on family” was inspired through the guidance of one family, that of Pathfinder Village resident Andrew Kennedy.
Mr. & Mrs. John R. Kennedy with son Andrew and friend David Zimmerman.
At Pathfinder Village, a unique residential community specializing in Down syndrome, Andrew enjoys a rewarding life with community employment, recreation, social activities, and many friends. The Center was named in memory of Andrew’s grandfathers, Jack Kennedy and Jimmy Willis.

At the Center’s dedication, Andrew’s father, John R. Kennedy, recalled the mentoring role his father and father-in-law had served, each sharing his wisdom, time, and good fortune with others in need. Focusing on family and sharing knowledge and resources remain at the core of the Center’s principles. We will always be indebted to the Kennedy family for their generous leadership and friendship.

These are exciting times in the human services field, and the Kennedy-Willis Center is fulfilling a larger role within the Down syndrome community. The Center is networked with other information centers, such as the Down Syndrome Medical Interest Group in Pittsburgh, and the New York State Institute for Basic Research in Developmental Disabilities, Staten Island, so that staff may respond to inquiries with the latest information. In concert with other national and international agencies and universities, the Center is helping to identify new diagnostic, treatment, and amelioration methods which will benefit individuals in meaningful and practical ways.

Much of the Center’s success is due to the dedication of loyal supporters—donors, clinicians, researchers, students, and families who have contributed to its work. Their extraordinary generosity has made many of the Center’s programs possible. This dedication has contributed significantly to the improvement of individuals’ lives and the growing body of knowledge about Down syndrome.
OUTSTANDING EDUCATION

One of the most effective means of disseminating information about Down syndrome and developmental disabilities is to provide educational opportunities at the Kennedy Willis Center. The hands-on curriculum focuses on several key areas: professional development courses and programs for Pathfinder Village staff; public workshops and conferences devoted to a broad range of topics and that cater to diversified audiences; volunteer and internship opportunities for young people who are considering careers in the human service field. Additionally, the Center receives current information through an extended network with other organizations and research facilities focusing on Down syndrome.

CONFERENCES AND WORKSHOPS

Through conferences and workshops featuring renowned experts in developmental disabilities, the Kennedy Willis Center disseminates knowledge and resources concerning Down syndrome to people from around the globe. Many conferences share important findings through regular progress reports by those conducting research, while other sessions offer practical solutions and advice to help care for and educate children and adults who have Down syndrome.
CONFERENCES AND WORKSHOPS

CELIAC DISEASE
Jennifer Bueche, PhD
Maureen Gavin, RN, C CDDN

BEHAVIORAL ASPECTS OF ANXIETY AND DEPRESSIVE DISORDERS IN ADULTS WITH DOWN SYNDROME
John A. Tsouris, MD

THE POWER OF PERSON CENTERED PLANNING
Carol Blessing, LMSW
Rosanne Westgate Pesola, PhD

TRISOMY 21 AND COGNITIVE DECLINE
Rosanne Westgate Pesola, PhD

EFFECTIVE READING PRACTICES FOR ADULTS WITH DOWN SYNDROME
Rosanne Westgate Pesola, PhD

LIFE PLANNING FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES
Bruce Erath, CLU, ChFC
Timothy Johnson, Esq.
Gordon R. Terry, CFSP
Joan K. Terry, CFSP
Paul J. Patti, MA
Adam A. Zaczkowski, CLTC

RELATIONSHIPS AND SEXUALITY IN INDIVIDUALS WITH DOWN SYNDROME
Joseph Anastasio, CMSW, MS
Stephanie King, LCSW-C, ACSW
Leslie Walker-Hirsch, M Ed

RESEARCH BASED TEACHING STRATEGIES FOR STUDENTS WITH DOWN SYNDROME
Natalie Hale, Literacy Advocate
Kathleen Feeley, PhD
Rosanne Westgate Pesola, PhD

PRESENTING AND UNDERSTANDING A PRE-NATAL DIAGNOSIS OF DOWN SYNDROME
Brian Skotko, MD, MPP
Fred C. Hirschenfang, MD, FAAP

A NEW APPROACH TO COMMUNICATION: ASL WORKSHOP
Heather Haux, MS, BA

ASSISTIVE TECHNOLOGY FOR LEARNERS WITH DISABILITIES
R.J. Cooper, Technologies Developer

THE ROCHESTER ENVIRONMENTAL AND SENSORY PROCESSING AWARENESS (RESPA)
Kathleen Bishop, PhD

PERSON CENTERED PLANNING
Bonnie Laugen, MS

DOWN SYNDROME, AUTISM AND COMMUNICATION STRATEGIES
Bonnie Laugen, MS

ALZHEIMER'S ASSOCIATION SERIES
Ann Thayer

GUARDIANSHIP AND HEALTH CARE ISSUES FOR PEOPLE WITH SPECIAL NEEDS
NY State Commission on Quality of Care and Advocacy for Persons with Disabilities

MEDICAL AND BEHAVIORAL ISSUES IN DOWN SYNDROME
George T. Capone, MD
INTERNSHIPS

The surest way to influence the future for those who have Down syndrome is to provide concentrated internships for students interested in careers in human services. The Kennedy•Willis Center has embarked on affiliation programs with colleges and universities throughout the Northeast, as well as in France and India, to offer rewarding learning and volunteer experiences for students. Those who meet the rigorous academic standards in this program receive credit from their colleges and universities.

INTERNSHIP PARTNERS

• Upstate Institute at Colgate University
• SUNY Geneseo
• SUNY Oneonta
• Hartwick College
• Edmeston Central School
• The Judy Center

VOLUNTEERS

The Center offers a range of community service programs to high school students, adults and service groups. While these projects offer volunteers a sense of purpose and opportunities to learn new skills, the overall goal of the Center’s volunteer program is to inspire individuals to be supportive of people who have developmental disabilities. In the case of young volunteers, it is hoped their experiences at the Center will strengthen their zeal towards making a better world.
INFORMATION AND ADVICE

The Kennedy•Willis Center provides direct support and advice for those families who care for loved ones who have Down syndrome and other developmental disabilities. The beginning of life is a precious time, and the Center staff can provide much-needed information to expectant and new parents as they welcome their infant who has Down syndrome. For each stage of a person’s life, the Center has answers about medical concerns and developmental milestones, educational and vocational programs, behavior management strategies, sexuality and safe relationships, spirituality, aging, and other important topics.

With recent advances in healthcare, people who have Down syndrome now often outlive their parents. The Center can assist families in making vital decisions for loved ones through discussions about life and estate planning, legal issues and finances, guardianship and living options, nursing care provisions, memorial services and associated arrangements.

The Center maintains a comprehensive website with up-to-date news, information and resource lists, and hosts webinars and video conferencing of leading experts in the field of Down syndrome.

The Nicolais Library houses an extensive inventory of professional books, journals and other printed materials on Down syndrome and developmental disabilities. The library also sponsors a disability film series throughout the year.
Research efforts at the Kennedy-Willis Center focus on non-intrusive studies by clinical professionals from accredited facilities studying Down syndrome. The collected data and findings about Down syndrome and related conditions have benefited the community, and have advanced our knowledge about lifelong learning for those who have disabilities, the aging process, and early onset dementia.

The Center’s chief research partner is the New York State Institute for Basic Research in Developmental Disabilities, Staten Island, which is operated by the state’s Office for People with Developmental Disabilities. Past and ongoing studies have focused on:

- Life Events in Older Adults Who Have Down Syndrome
- A Self-talk Survey
- A Gastrointestinal Symptoms Survey
- Alzheimer’s Disease in Persons Who Have Down Syndrome
- Estrogen-loss Studies on Women Who Have Intellectual Disabilities
- Aging in Adults Who Have Down Syndrome
- A Comparison of Informant-based Scales
BOARD OF ADVISORS

Darlynne Devenny, PhD
Joseph Dutkowsky, MD
Dawn Hamlin, PhD
Elizabeth Ingram
Thomas Inkpen, EdD
Paula Kennedy-Harrigan
Andy Lopez-Williams, PhD
Philip McCallion, PhD, ACSW
Nancy Ray, EdD

FRIENDS AND PARTNERS

AIM High
Al Noor Training Center
for Children with Special Needs
American Association on Intellectual
Developmental Disabilities
The Arc Otsego
Association for Children with
Down Syndrome, Inc.
Bassett Medical Center
Broome Community College
Children’s Hospital, Boston
Colgate University
Cornell University
Council for Exceptional Children
Creating Solutions
Down Syndrome Centre (Ireland)
Down Syndrome Medical Interest Group
Down Syndrome Resource Center, Inc.
Edmeston Central School
Family Resource Network
Hartwick College
Holy Cross College (South India)
Hope Haven Children’s Clinic and Family Center
Institute for Basic Research
in Developmental Disabilities
The Judy Center for Down Syndrome
Kennedy Kreiger Institute
National Down Syndrome Congress
National Down Syndrome Society
National Task Group on Dementia and
Intellectual Disabilities
Reece’s Rainbow
Special Reads for Special Needs
State University of New York
Strong Center for Developmental Disabilities
and Golisano Children’s Hospital
The Association for Persons with Severe Handicaps
Upstate Cerebral Palsy
University of Rochester Medical Center
Villanova University

BOARD OF DIRECTORS

CHAIR
William F. Streck, MD

VICE CHAIR
Douglas B. Willies

SECRETARY-TREASURER
William F. McCord

DIRECTORS

David A. Bryant, OD
Stephanie K. Davis
Robert S. Hanft
Alan R. Leist, III
Nancy C. Mirabito
Senator James L. Seward

PRESIDENT AND
CHIEF EXECUTIVE OFFICER
PATHFINDER VILLAGE
Paul C. Landers, M Ed
Knowledge concerning those who have Down syndrome is disseminated through conferences, workshops, staff development programs, networking and outreach. The Center provides information regarding developmental disabilities to parents and families, the public, professionals and the Pathfinder Village staff in conjunction with an extended network of organizations and research facilities focusing on Down syndrome. The Center’s work assists in refining the understanding of the needs of individuals who have Down syndrome, resulting in an improved quality of life for those who live at Pathfinder Village and around the world.