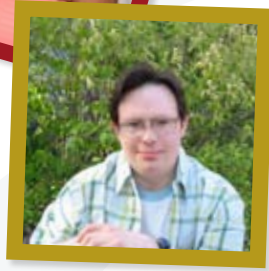




**Meet Josie. Meet Joe.**



Annual Report  
August 2007 – July 2008



**Meet Joe,  
Josie,  
John,  
Joanna,  
Roberto and Roberta.**

**By any name, meet people with Down syndrome.**

*Gather 30,000 people  
– say at a ball game –  
3 or 4 will have  
Down syndrome.*

*Some will be babes.  
A few, teenagers.  
Others, adults.*

*They will have much  
in common. Not so  
much with each  
other, but with  
the rest of the crowd.*

As a cross section of the population, however, each stands as a milestone marking the progress made over decades toward helping people with Down syndrome become fully participating members of their communities.

Through all of that – and for more than 35 years – their champion has been the National Down Syndrome Congress.

We are thousands of parents, siblings, professionals. And, of course, people with Down syndrome.

For nearly 40 years we have worked tirelessly and with unqualified love on behalf of our family members and friends with Down syndrome to ensure the rights of all people with Down syndrome. To improve their health, open doors, connect them with their communities, improve education, find jobs and so very much more.

**On the following pages, you will find a synopsis of the NDSC's past, our exciting present and where we will go in a very promising future.**

*Dear Members,*

*Commonly, our community is defined by one word – disability.*

*It's time that changes.*

*This year, the National Down Syndrome Congress launched a national advertising campaign under the banner We're More Alike Than Different. The message is simple – people with Down syndrome are like everybody in all ways that count.*

*The campaign is but an example of how our community is making a profound transition. For most of our history we have focused on ourselves – on creating hope, then aspiration and, finally, on holding passionately to the knowledge that our children can succeed as full participants in their world.*

*It is our guiding principle and has served us superbly.*

*If you need proof, go to our web site and preview the More Alike campaign TV spots. You will see four people whose lives are shaped by what shapes the lives of all – jobs, loves, family, community.*

*They are complete people.*

*That shows we have won a great victory. Now we are bringing the rest of the world our good news.*

*That is crucially important as battles remain. This year, we engaged in many – we fight to have complete and fair facts given to expectant families, to bring under-served segments of our community into our family, to unite our movement and amplify our strengths. And, we work to fund the More Alike campaign so we can deliver our wonderful message.*

*I have, over three years of serving as your president, deeply appreciated the support so many have given. I trust that, as the NDSC moves into its future, your wonderful support will continue.*

*Sincerely,*



*Rich Robison*

*President*

People with Down syndrome 35 years older and their families are the pioneers who can recall the early frontier of our movement. Many were born into a wilderness – a world fraught with misinformation and ill-founded prejudices.



### Ages 35+

Older folks with Down syndrome – people in their late 30s and older – can tell us, from personal experience, just how very far we have come in a very short time.

The National Down Syndrome Congress was founded in 1972 by parents and professionals who understood their special needs. Back then, our founders were a committee of ARC national. Today, the NDSC and our affiliated organizations work closely with ARC and other organizations serving people with

disabilities, nationally and regionally, to secure and defend the rights of people with Down syndrome in our schools, at work and in the community at large.

NDSC is working in an “ad-hoc” coalition to improve the services for adults.

In 1990 The NDSC was a key part of the coalition that won passage of the pioneering Americans With Disabilities Act which stands today to mark the end of the wilderness for people with Down syndrome.

# 25 TO 35

## **Ages 25 to 35**

People with Down syndrome who are now in their late 20s and early thirties were the first to benefit from key actions like passage of the Americans with Disabilities Act and Individuals with Disabilities Education Act (IDEA).

IDEA set down a basic principle – that all students, regardless of ability, have a right to an education in the least restrictive environment.

Members of the National Down Syndrome Congress coined a new term – mainstreaming – the idea that our children with Down syndrome could and should prosper in regular classrooms with their peers.

Our self advocates pioneer in this age bracket, some by turning the myth that people with Down syndrome cannot excel in post secondary education into yet another worthless hunk of misinformation.



**They were among the very first citizens with trisomy 21 to be, commonly, raised by their families – to see the doors of the schoolhouse open wide and accept them as capable, often avid learners.**

## **Ages 18-25**

This is the crucial transition stage for people with Down syndrome and for our movement. It is a golden period.

In high school and transition programs, our friends with Down syndrome routinely astound. They blossom as artists and writers while participating fully in their schools, often imparting their classmates with a whole new understanding of the value of people.

NDSC is represented in work groups seeking to improve the quality of services for transition age students with disabilities and for requiring school-wide positive behavior supports for students.

**Young adults with Down syndrome of this age have reaped the benefits of all that has gone before.**

**By any standard, it is tough to be a teenager and it is no less so for people with Down syndrome. Life becomes complicated as academics become increasingly abstract and choices multiply.**



*The pages of Down Syndrome News, the NDSC newsletter, and our archives are filled with stories of young men and women with Down syndrome serving as homecoming royalty and delivering commencement addresses.*



Virtually every year, the National Down Syndrome Congress joins as a plaintiff or submits amicus briefs in support of suits aimed at enforcing **statutes** that assure people with Down syndrome full access to public education.

### **NDSC Governmental Affairs Coalitions and Collaborative Activities**

The NDSC works in alliance with a wide range of like-minded organizations in on-going efforts to assure that people with Down syndrome are able to participate fully in their communities.

This past years those activities included:

- **The Consortium for Citizens with Disabilities**
  1. Health Task Force
  2. Education Task Force
  3. Employment and Training Task Force
- **Collaboration to Promote Self-Determination** — Promote the empowerment of individuals with intellectual disabilities in employment, community living
- **CCD Ad hoc Transition Task Force** — Develop legislative language for education and employment legislation
- **Universal Design for Learning Task Force**
- **Schools for Success Coalition** — Promote legislation that includes language addressing the use of school wide positive behavior support
- **APRAIS** — The Alliance to Prevent Restraint, Aversive Interventions, and Seclusion — To seek the elimination of the use of seclusion, aversive interventions, and restraint to respond to or control the behavior of children and youth.

**Ages 5-18**

New parents often make the NDSC their first call when seeking information critical to raising their children with Down syndrome. Some become members; others, referred to their local Down syndrome organization may not resume contact until an NDSC convention is held in a nearby city. Either way, we listen, offer counsel and, of course, open access to all of our information.

Pioneering work by courageous researchers – many of whom have become regular presenters at the NDSC Convention and serve on our Professional Advisory Council – have reversed assumptions once taken as fact about the ability of our children to learn.

**Over the past four decades we have seen a revolution in teaching techniques that has opened an ever-widening world of learning to students with Down syndrome.**

Our 35th annual convention, held in Kansas City, was host to more than 2000 people – nearly 1700 attended the general convention with its plenary and workshop sessions, more than 230 self advocates participated in the Youth & Adults conference and almost 110 siblings came together for the Brothers & Sisters conference.

One of many high points was the announcement of a \$250,000 challenge grant from a very generous NDSC family to fund a national awareness campaign for Down syndrome. By the time the 2007 NDSC awards banquet was over we had raised \$55,000 toward matching the challenge.



## Ages 0-5

Early childhood programs give kids with Down syndrome the high-energy start in life they need to stay on par with their playmates and often make a world of difference by preparing them to enter school on par with their classmates.

Representatives of the Congress exhibited at the American College of Obstetricians and Gynecologists (ACOG) and the National Society of Genetic Counselors conventions in San Diego and Kansas City. The appearances are an important part of our on-going initiative relative to advisories from ACOG that prenatal screening tests for Down syndrome be offered to all expectant mothers, Copies of *Gifts*, provided by editor Kathryn Lynard Soper, were distributed at both events.

In support of our diversity outreach initiative, we expanded the NDSC web site to include a Spanish-language branch that now virtually replicates the English-language site. The site also includes a link to the Federacion Espanola de Sindrome de Down, a site rich in important information on Down syndrome for the Spanish speaking world. The Congress also helped facilitate Russian translation of *Babies with Down Syndrome* and translation of a new parent package into Bulgarian. Finally, the NDSC has worked to build and reinforce an international network of organizations who focus with us on issues and challenges. Members of the staff and board went to Puerto Rico to join an inaugural Down Syndrome Awareness Month celebration.



*In a real way, attitude – the collection of facts and ideas, thoughts and impressions we use to shape decisions and actions – is everything.*

*For too long, attitudes based on falsehoods, fears and prejudice have persisted about people with Down syndrome.*

In 2007, the National Down Syndrome Congress launched a national awareness campaign to level that final barrier to inclusion in our schools, access to meaningful employment and participation in our communities.

**Our ads reach millions of professionals – ob-gyns and K – 12 teachers. Five powerful TV spots have been distributed to organizations affiliated with the NDSC and the campaign is gathering momentum as they place those in local and regional media.**

The campaign is telling the world what

we know – folks with Down syndrome are complete, capable and wonderfully ordinary people whose lives are to be cherished – **More Alike Than Different.**



### 2007 – 2008 Selected Governmental Affairs Activities

**IDEA Fairness Restoration Act** – NDSC is one of the organizations responsible for the introduction of this bill in the House of Representatives.

**No Child Left Behind** – submitted proposed regulatory language, promoting high quality standards for students with intellectual disabilities.

**Pre and Post Natal Screening (known as the Kennedy-Brownback bill)** – NDSC actively advocated for passage of this bill that provides for information and support for families when they receive a diagnosis of Down syndrome.

**Financial Security Accounts for Individuals with Disabilities Act** – House and Senate bills introduced that allows families to save for their child without jeopardizing much-needed long term benefits.

**Medicaid (long-term services)** – NDSC has joined other national organizations in letters to Congress and Administration officials opposing further erosion in the funding for long-term supports for individuals with disabilities. We also actively support efforts to increase funding for Direct Support Workers and provide funding directly to families/individuals with disabilities to control their own resources.

**Workforce Investment Act/Vocational Rehabilitation Act** – We have worked actively to promote quality transition and employment services for students and adults with long-term support needs.

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