

Down Syndrome *Information Network* of the Twin Tiers

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New Members



We have several new babies in the area and the families have joined our group. If you have any information or advice that you would like to pass

along, please send it to Chris (739-2229 or hecklece@stny.rr.com) and we'll get it to the families. We welcome a 4 month old girl in Elmira, a 2 month old boy in Bath, a 1 year old girl in the Northern Tier, and a 6 year old girl who just moved to Corning. ✽

On the Web...Simply Adorable Blankets



This company was started by two moms, each with a daughter with Down syndrome. The girls make blankets and other objects to show their creativity and create a place for themselves in the community. Please visit <http://simplyadorableblankets.org/home.html> for more information.

Next Monthly Meeting:

June 20, 2007 6pm Chemung ARC

Meetings are held on the 3rd Wednesday of the month. The next meeting dates are:

June 20th from 6 to 8 p.m.
Buddy Walk Meeting
July 18th from 6 to 8 p.m.
Buddy Walk Meeting

Meetings are held at Chemung ARC located at 711 Sullivan Street in Elmira, and pizza/wings and child care are provided.

Sponsored by:



Recent Supreme Court Decision

www.wrightslaw.com

The Supreme Court has ruled in *Winkelman vs. Parma* that parents can represent themselves or their child without an attorney. The Winkelman decision also affirmed parental rights, the importance of parental involvement, and described the essential role parents play in ensuring that their child receives a free appropriate public education (FAPE). The Court also refined the definition of a "free appropriate public education." This case law strengthens the basic principles of IDEA. Please see the Wright's Law website for more information and analysis. ✽



Sandee & Jacob Winkelman

2007 Rene Jones Memorial Buddy Walk

The Buddy Walk is going to be held in conjunction with the Chemung Canal Fall Fest again. This year, the Fall Fest is from 10 a.m. to 6 p.m., which may help draw some additional people to our Buddy Walk in the morning. Deputy Lathrop agreed to bring some of her therapy dogs to the Buddy Walk, so be sure to come and see the animals.

We're doing the raffle again this year as a fund-raiser. We'll be asking people to sell tickets again this year, so please watch for that. If you'd like to help, please contact Michelle (739-0272) or Chris (739-2229).



Down Syndrome History: The role of Dr. Lejeune

by Carolyn Moynihan

published on www.mercatornet.com

Dr. Jerome Lejeune's scientific and spiritual fame centers on his 40-year commitment to finding a cure for Down's syndrome (for pedantic reasons now known as "Down syndrome" in North America and elsewhere). At the very beginning of his medical career in the 1950s he found himself drawn to the young, mentally handicapped children, so often segregated in institutions and denied treatment which could have relieved associated health problems. He also felt deeply for the parents who learned that they had given birth to a "Mongol" child ("Mongolian idiocy" was the cruel technical term for the condition) and who fell under suspicion of breeding racial degeneracy. In earlier decades Down's sufferers had been targets of the eugenics movement.

[Dr. Lejeune] sought to open people's eyes to the human dignity of those affected by the syndrome and their claim on our love and effort.

Fellow feeling for these innocent outcasts turned the young Parisian doctor into a research scientist, his mind and heart set on solving the mystery of their condition and relieving their suffering. He would not accept that his profession could turn its back on one whole group of people. Already some scientists speculated that Down's was caused by a fault in the chromosomes. Following this lead and using the new technique of karyotyping he discovered, in 1958, that a patient with Down's had an extra chromosome at the 21st pair. The genetic diagnosis known as Trisomy 21 was born, establishing the first ever link between mental disability and a chromosome disorder — and heralding a new era in genetics.

It was a discovery of incalculable importance to people with the condition and their families — if only at first from a symbolic point of view. The embarrassing and misleading term "mongolism" was gradually retired (although it still crops up) and the term Down's adopted after John Langdon Down who first described the syndrome.

But Lejeune's contribution went beyond the scientific into the realm of what we might call "public relations" as he sought to open people's eyes to the human dignity of those affected by the syndrome and their claim on our love and effort. As he and colleagues turned his surgery at the Necker Hospital for Sick Children (Paris) into one of the largest cytogenetics centers in the world, studying more than 30,000 chromosomal cases and treating more than 9000 patients with genetically-linked intellectual disabilities, the medical profession became involved in a great betrayal, using the new science for prenatal diagnosis leading to abortion. By the 1990s as many as 90 percent of Down syndrome babies in Britain were deliberately aborted. Since 2003 every pregnant woman in Britain is offered a screening test whose main purpose is to make abortion possible.

This trend was a source of tremendous anguish for Lejeune and drove him to defend his patients publicly from what he called "chromosomal racism". This put him in demand as a

speaker and expert witness for the pro-life movement — adding to his already enormous workload of teaching, research and clinical work — but led to his being ostracized by many of his peers. "Medicine has become mad," he said, "when it attacks the patient instead of fighting the disease. We must be on the patient's side, always." Fighting on two fronts his life must have become a kind of martyrdom — albeit one marked by joy and good humor — shared by his staunch wife and five children.

Lejeune was convinced that a cure for Down's syndrome was possible and that it would open the way to a cure for all the other genetic diseases. "It is obvious that we'll find a way," he said. "The intellectual effort is much simpler than putting a man on the moon." And, "The patients are waiting for me, I have to find the answer." However, although he labored to the last weeks of his life — exploring the use of folate therapy, for



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example — he died in April 1994 without achieving his mission, and feeling that he was "abandoning them".

It would console the saintly scientist, however, that there seems to be a sort of grassroots rebellion brewing against the culture of death that has stifled the lives of countless thousands of Down's babies prenatally. Articulate middle class parents, who tend to have their children later and to that extent run a greater risk of Down's, have been speaking up in the media about their disabled children. A fine example appeared in the London Times last year, a testimony by the paper's chief sports writer to the joy he has had from his second son, who has Down's.

The writer, Simon Barnes, is at pains to make it clear he is "not a saint", just a dad who enjoys life and takes it as it comes — including in the form of an intellectually impaired son, whom he has found it quite natural to love. While respecting his sensibilities about "sainthood" one should perhaps warn him that sanctity could still sneak up on him. After all, Jerome Lejeune did no more than love the children in front of him in a perfectly natural way — as a man, a father and a professional.

There is much more to say about the geneticist who could be a saint. But this much can be said with confidence: that his profession was never in greater need of the ideals he represents and a model for living them than it is now. ❀



TEAM CAPTAIN COMMITMENT FORM

Please sign me up to be a Team Captain!

NAME: _____

TEAM NAME: _____

ADDRESS: _____

CITY, STATE, ZIP: _____

HOME PHONE: _____ WORK PHONE: _____

E-MAIL: _____

So that we may serve you better, please tell us a little bit about yourself:

- √ THIS IS MY ____ YEAR TO DO THE BUDDY WALK.
- √ I HOPE TO RECRUIT A TEAM OF _____ MEMBERS.
- √ MY GOAL IS TO RAISE \$_____ FOR DOWN SYNDROME.
- √ MY INSPIRATION: _____.
- √ I WANT TO RECEIVE INFO BY E-MAIL _____ OR MAIL _____

Please send this form in as soon as you have decided to put together a team. Once we receive your form, we will send you the tools to help you succeed!

Mail or fax your Team Captain Commitment Form to:

Michael Battersby
215 Scott Lane
Horseheads, NY 14845
Fax # 607-739-8737

BUDDY WALK TEAM MEMBER SIGN UP SHEET

(duplicate form as needed)

Team Captain _____

Team Name: _____

Home Phone: _____

Work Phone: _____

Instructions:

This form can be used instead of the Registration Form on the brochure. All participants must sign the signature of waiver statement. If the participant is under the age of 18, the parent or guardian’s signature is required.

First Name	Last Name	ADDRESS (CITY, STATE, ZIP)	TELEPHONE	E-Mail	Signature of waiver statement (bottom of page)

Waiver: In consideration of me and/or my minor child being permitted to participate in the Buddy Walk, I hereby – for myself, my heirs, and personal representatives – assume any and all risks which might be associated with the event. I further waive, release, discharge, and covenant not to sue the Down Syndrome Information Network (DSIN) of the Twin Tiers, Chemung ARC, NYSARC, and/or the National Down Syndrome Society, their officers, employees, sponsors, organizers, volunteers, or other representatives or their successors and assigns for any and all injuries or damages of any kind whatsoever suffered by myself and/or my minor child as a result of taking part in the events and any related activities. I promise to abide by any Buddy Walk rules set forth and explained by Buddy Walk, DSIN of the Twin Tiers and/or Chemung ARC organizers. I also give full permission for use by the DSIN or Chemung ARC of my name, photograph, film or videotape taken of me or my minor child at the event for any purpose.