

# Newsletter

## Winter 2002

Edited by: Brian Chicoine, MD

### Thank you

Thank you for your continued generous support. Your support is helping us expand our services. We are looking forward to hiring a nurse practitioner to increase the availability of our services. We are going through the interviewing process now.

We are also working to organize and disseminate the information we have gathered by seeing more than 1300 people with Down syndrome. A new computer database is being developed so that we can better understand health and psychosocial issues in people with Down syndrome. We are also trying to disseminate the information in a variety of ways: the newsletter, presentations, and other ways we are looking to develop.

Thanks for all your assistance.

### Upcoming Presentations

Dennis McGuire, Ph.D. and Brian Chicoine, MD are presenting at two upcoming conferences.

#### **Promoting Health in Adults with Developmental Disabilities**

Additional Speaker: Carol Gill, Ph.D.

Sponsor: The Arc of Illinois  
Date: March 12, 2002  
Time: 9 AM to 4 PM  
Location: Holiday Inn Hotel and Conference Center  
7800 Kingery Highway  
Willowbrook, IL 60521

For information and registration contact The Arc of Illinois  
1820 Ridge Rd  
#300  
Homewood, IL 60430-1739  
708-206-1930

#### **Psychosocial and Medical Issues for Adults with Down Syndrome**

Sponsor: Heart of Illinois Down Syndrome Association, Central Illinois Down Syndrome Organization and Parc's Advocacy Committee in collaboration with the Institute on Disability and Human Development in the Department of Disability and Human Development at the University of Illinois-Chicago.

Date: April 26, 2002  
Time: 9 AM to 3 PM  
Location: Parc  
1913 W. Townline Rd  
Peoria, IL

For information and registration  
contact Community Education Program  
Institute on Disability and Human  
Development  
1640 W. Roosevelt Rd.  
Chicago, IL 60608  
312-413-1535  
(TDD) 312-413-0453

## **Pain**

Brian Chicoine, MD

Do people with Down syndrome  
have a greater pain tolerance than other  
people?

Do people with Down syndrome  
have a normal pain tolerance but we  
misinterpret their complaints?

The answer to both of these  
seemingly opposing questions is  
probably “yes”.

Many families and care-providers  
have commented to us that they think the  
person with Down syndrome they know  
has an increased pain tolerance. We  
have seen many examples that support  
those observations. Many patients have  
been seen with health problems that  
would seem to be quite uncomfortable  
but who had little or no complaint of  
discomfort.

Furthermore, a recent study provided  
supporting evidence in a “mouse model”  
for Down syndrome. Mice with a  
trisomy (extra chromosome) have been  
studied. They have been found to have  
to have similar health issues as people  
with Down syndrome. This mouse  
model was found to have a higher pain

tolerance. The mouse had less response  
to painful stimuli.

While all that seems to support a  
higher pain tolerance, we also suspect  
that some of the apparent pain tolerance  
may be due to our inability to interpret  
the complaints of some people with  
Down syndrome. It may be an  
impairment of verbal communication  
skills or the absence of someone who  
understands the persons communication  
attempts. Another possibility is the  
reduced ability of some people with  
Down syndrome to appropriately self-  
assess where the pain originates and,  
thus, a limited ability to make others  
understand that he is experiencing pain.  
The person may be experiencing pain  
but we are just not understanding.

### **How can we avoid missing painful episodes?**

- Watch for subtle signs

A grimace, pointing, a different  
spoken phrase, sweating for no apparent  
reason, and holding a limb differently  
can all be signs to note. There are  
probably many more that you have  
noticed as well.

- Watch for behavioral changes

Pain can often be expressed in a  
behavioral change. When I teach  
medical students or residents, I always  
emphasize that a change in behavior has  
to be viewed as a form of  
communication. This is true to some  
extent in all of us. People with Down  
syndrome are no different. However, the  
person with Down syndrome’s ability to  
communicate verbally or non-verbally  
may be limited so he may end up telling

us with a behavioral change. It could be less activity, more activity, seeking greater attention, seeking less attention, a sad affect, anger, emotional lability, reduced emotion, and many others.

- Consider the possibility that a person with Down syndrome may have a reduced ability to perceive pain

Remembering that the person with Down syndrome may also have a reduced ability to perceive pain is important as well. Keeping an eye on someone whom has what appears to be a minor complaint can help prevent missing something more concerning. If the pain persists longer than expected or there are other symptoms that could suggest something more serious despite the person having little complaint, it could be time to have it further evaluated.

Remembering a few ideas about communication can help us avoid missing painful episodes.

- A reduced ability to communicate symptoms may be the real cause of an apparent increase pain threshold in some people with Down syndrome.
- A reduced ability to communicate may cause a misinterpretation of the symptoms.

### **What are the Implications?**

- Pain tolerance may or may not be less. It is important to consider physical problems and optimize physical health when evaluating behavioral changes.

- Communication: consider displays of behavioral changes as potential communication devices (of physical or mental pain).

## **Memorial Donations**

Thank you to all that support our work at the Center. Thank you to the families who have remembered us in memorials. We have received donations in memory of the following people:

Shizue Hirano and Masaye Saito

Ted Iida

Dr. Mas Harada

Ted Kido

Helen Ryan

James McNeal

Anthony Tarullo

Roger Booty

We also received a remembrance donation in honor of:

Harold Schaffner

Thank you for your generosity.

## **Upcoming Issues**

If there are topics you would like to see presented in future issues of our newsletters, please contact us at the Center. You can reach us at:

847-318-2303

or by email:  
brian.chicoine@advocatemedical.com