

## Newsletter

Fall 1998

Editor: Brian Chicoine, MD

### National Down Syndrome Awareness Month

October is National Down Syndrome Awareness Month. Please note a couple of events taking place in October.

The National Association for Down Syndrome's 1998 conference is October 24 from 8 AM to 4:30 PM. There are many interesting presentations planned. These include the plenary sessions, workshops, and a conference for teens and adults with Down syndrome. The workshops focus on issues relating to infants, children, adolescents and adults. Contact the National Association for Down Syndrome at 630-325-9112 for further information. If you would like to volunteer to help at the conference for teens and adults, call Linda at 630-830-0421.

Buddy Walk '98, "Equality thru Visibility"; sponsored by Family T.I.E.S. Network is taking place October 3 from 11 AM to 3PM in Berwyn. This is a fun filled family public awareness event supporting all persons with disabilities. Contact Anita Johnson-Jackson (773-287-4290), Catherine Bedard (707-484-4570) or Leah Jeffries (708-484-1091).

The National Association for Down Syndrome conference is called "Focusing on the Possibilities". Sounds like great theme for the Down Syndrome Awareness month.

### Resource Center

By Ann Jonaitis

Through generous grants from the Twentieth Century Juniors Foundation and the Goldberg Family Foundation, we are developing a resource center in our waiting room. Instead of just "waiting", we hope that all that come here will find enjoyable and interesting things to do. There is a melodious xylophone to play, computers with software and access to the Internet and a VCR with some special, one-of-a-kind videos featuring people with Down syndrome. The bulletin boards spotlight attractive pictures of our patients, interesting conferences, on-going research, and tips for leading a healthy life.

One corner of the room houses the NADS (National Association for Down Syndrome) Resource Library with books and tapes that may be borrowed in person or by phone. We also have 50 paperback fiction books, written at the first and second grade reading levels. They are mystery, travel, sports, adventure, and science fiction books. We hope some of our patients will check out these and enjoy them. Next to the bookshelves is a file cabinet with dozens and dozens of articles and brochures, some of them in Spanish. A large binder holds additional articles written by our own doctors. These are popular items and we make copies of them for many people.

We are looking for suggestions for materials that you are interested in that we might purchase. We are also looking for input on web sites that you have found helpful that we could "bookmark" for others to review. It will continue to be a growing resource for us and for you. Your input on that growth is appreciated. Please call Ann Jonaitis at 847-795-2431 for information, to check out materials, or to make suggestions.

## **Research project**

Several people signed up for our study on ApoE4 protein and IQ level. However, we would like to recruit additional participants. Our study will look at the protein in persons with Down syndrome, their level of function as demonstrated on previous IQ tests and their present level of function. With this study and ongoing review of the information we gather as we treat people everyday, we hope to further our understanding of Alzheimer's disease and to optimize the health of our patients.

If you are interested, please contact Dr. Nancy Johnson at 312-908-9432.

## **Osteoporosis**

Osteoporosis, "thinning of the bones", is a problem that we all experience to one degree or another as we age. The concern about osteoporosis lies in the fractures that occur because of the weaker bones. More than one third of adult women in the general population will sustain a fracture in their lifetime secondary to osteoporosis. Men are also susceptible to osteoporosis but not as often as women are. There is some evidence that suggests that persons with Down syndrome are more at risk for osteoporosis.

What can you do to prevent it?

## **Maintenance of mobility**

Regular exercise is important. Weight-bearing activities, such as walking or jogging, improve skeletal (bone) health. Non-weight-bearing activities, such as swimming, improve well being and increase confidence and coordination.

## **Nutritional advice**

The Recommended Daily Allowance for vitamin D is 400 International Units. Some regular exposure to sunlight also helps. Exposure of our skin to sunlight converts a non-active form of dietary vitamin D to an active form. You can get vitamin D in your diet or, if you can not get enough in the diet, you can get it by taking supplements.

Adequate calcium intake is also important. While the recommendations vary with age, a reasonable intake is at least 1200 mg of calcium daily. A large glass of milk has about 600 mg. Calcium seems to be best absorbed if taken at the same time as vitamin D.

## **Hormones**

In women who are menopausal, estrogen replacement therapy is available to help maintain bone strength.

## **Medications**

If a person develops osteoporosis, there are a number of medications now available to help regain bone strength.

Osteoporosis can be a very serious medical problem that can lead to very disabling fractures and even life-threatening fractures. Regular exercise and good nutrition are readily available preventative measures. (For regular readers of our newsletter, we seem to frequently come back to the importance of these two areas for a variety of health and well-being issues).

Reference: Kanis JA, Delmas P, Burckhardt P, et al. Position Paper:

Guidelines for diagnosis and management of Osteoporosis. Osteoporosis International 7: 390-406, 1997.

## **Influenza Vaccine**

The "flu" season is nearly upon us again. This is the time to consider prevention ... the flu shot. The flu shot is recommended for any person over the age of 6 months, who because of age or underlying medical condition is at increased risk for the complications of influenza. Health care workers and others (including household members) in close contact with persons in high-risk groups also should be vaccinated. In addition, influenza vaccine may be administered to any person (older than 6 months of age) who wishes to reduce the chance of becoming infected with influenza.

We recommend influenza vaccine for our patients. We definitely recommend it for all those with other health problems that would warrant it, those over 65 and those living in a group facility. We recommend that all our other patients also consider it in light of some evidence of immunodeficiency (weaker immune system) and the frequent exposure of many of our patients to other people with chronic illnesses who should not be exposed to influenza.

### **Groups at increased risk:**

- Persons 65 years old or older
- Residents of nursing homes and other chronic-care facilities that house persons of any age whom have chronic medical conditions. (This would include anyone with Down syndrome living in a group residential facility. Anyone who works in a workshop should also consider it).
- Adults and children who have chronic disorders of the pulmonary or cardiovascular systems, including children with asthma. (Down

syndrome is not a condition in itself that requires influenza vaccine but persons with Down syndrome who have heart or lung problems should get the flu vaccine).

-Adults and children who have required regular medical follow-up or hospitalization during the preceding year because of chronic metabolic diseases (including diabetes mellitus), renal dysfunction, hemoglobinopathies, or immuno suppression (including those caused by medications). (This is the area that may include many persons with Down syndrome. There are studies that have shown persons with Down syndrome tend to have weaker immune systems and, therefore, influenza vaccine may be indicated for all persons with Down syndrome on that basis).

-Children and teenagers (aged 6 months to 18 years) who are receiving long-term aspirin therapy and therefore, might be at risk for developing Reye syndrome after influenza.

-Women who will be in the second or third trimester of pregnancy during the influenza season.

### **Persons who should not be vaccinated**

-Persons with known anaphylactic (severe allergic) sensitivity to eggs (this does not include people who don't like eggs or get gastrointestinal distress after eggs-these individuals can still get the vaccine).

-Adults with acute febrile illnesses (high fever). (Minor illnesses with or without fever should not prevent getting the vaccine).

### **Side effects**

Influenza vaccine contains only noninfectious viruses and therefore, cannot cause influenza. It can cause:

-Soreness at the injection site that lasts up to 2 days.

-Fever, malaise (feeling poorly), myalgias (muscle aches), and other systemic symptoms.

The symptoms usually begin 6-12 hours after the vaccine and can persist for 1-2 days.

-Immediate, presumably allergic reactions such

as hives, swelling, asthma can occur in rare occasions.

-There may be (although it is not clear) a slight increase in the incidence of Guillain-Barre syndrome after influenza vaccine.

Please contact us for questions or to set up an appointment for a flu shot. You might also check a local pharmacy or other provider closer to your home (especially if a lengthy travel is necessary to the Center).

Reference: Supplement to Morbidity and Mortality Weekly Report, May 1, 1998JVol. 47/No. RR-6.

## **Book Review**

I am in the process of rereading The Power of the Powerless. I know I have enjoyed a book when as soon as I get to the last page, I turn back to page one and start reading again. This is such a book.

Chris de Vinck writes about his brother, Oliver, who had a severe intellectual and physical disability. Mr. de Vinck describes how much effect his brother had on others despite the fact he was one that society would generally see as "powerless". The book started with an essay that appeared in the Wall Street Journal. He expanded the essay and included stories from others that wrote him about their similar experiences. Included in the book is a man's story about his brother, Paul, with Down syndrome.

Mr. de Vinck has many interesting insights. One that I found particularly interesting was a story about how his brother helped him more clearly see the character of a girlfriend.

"When I was in my early twenties, I met a girl and I fell in love. After a few months I brought her home for dinner and to meet my family.

After the introductions, the small talk, my mother went to the kitchen to check the meal, and I asked the girl, "Would you like to see Oliver?" for I had, of course, told her about my brother.

"No" she answered. She did not want to see him. It was as if she had slapped me in the face, yet I just said something polite and walked to the dining room.

Soon after, I met Roe, Rosemary-a dark-haired, dark-eyed, lovely girl. She asked me the names of my brothers and sisters. She bought me a copy of the Little Prince. She loved children. I thought she was wonderful.

I brought her home after a few months to meet my family. The introductions. The small talk. We ate dinner; then it was time for me to feed Oliver.

I walked into the kitchen, reached for the red bowl and the egg and the cereal and the milk and the banana and prepared Oliver's meal. Then, I remember, I sheepishly asked Roe if she'd like to come upstairs and see Oliver. "Sure", she said, and up the stairs we went.

I sat at Oliver's bedside as Roe stood and watched over my shoulder. I gave him his first spoonful, his second. "Can I do that?" Roe asked. "Can I do that?" she asked with ease, with freedom, with compassion, so I gave her the bowl, and she fed Oliver one spoonful at a time.

The power of the powerless. Which girl would you marry? Today, Roe and I have three children."

I really enjoyed this book and it really helped put into words many of my own observations and thoughts.

The Power of the Powerless, Christopher de Vinck, 1988, Zondervan.

## **Clinic Update**

We have now served over 700 patients with Down syndrome. We celebrate our 7th anniversary in January 1999. We thank you for your support.

## **Any writers out there?**

I invite persons with Down syndrome, family members, care providers and others who are interested in contributing to our newsletter to contact me. Do you have a story that would be of interest to others? A common experience? A helpful recommendation? I would love to hear from you.