

Newsletter Fall 1999

Editor: Brian Chicoine, MD

We're Moving

We are moving the Center back to the Lutheran General Hospital campus. It is no longer possible for us to remain in our present building. Lutheran General Hospital has provided us with a building on the campus. The building has not been used for clinical services in several years and is requiring some extensive rehabilitation. We are hoping to move into the building in early December. When we have a definite moving date, phone numbers, etc. we will let you know.

We are looking forward to the move. We will have about the same amount of space but we will be in our own building. It is located at 1999 Dempster St. in Park Ridge and is on the same side of Dempster as the hospital. It is easily accessible from I-94 and I-294.

We will have space for our evening programs including aerobics and music therapy. The National Association for Down Syndrome will have an office in the building. We will again have space for our resource center with books, computers with Internet access, tapes and other materials.

We look forward to giving you more information, as it becomes available.

Flu Season

The flu (influenza) season is fast approaching us again. The recommendations for preventing the flu for this season are now available. The flu vaccine is the primary means of preventing the flu.

- The optimal time to receive the vaccination is from October through mid-November. (This allows the body to optimize immunity against the flu by the peak "flu season" between late December and early March).
- If you miss the recommended time, it is still a good idea to get the flu shot by early in the year 2000.

For our patients, we recommend the flu shot for the following people:

- Persons 50 years of age or older (the official recommendation is 65 but because of early aging issues in people with Down syndrome I think it is reasonable to consider the flu shot at 50).
- People with chronic health problems such as heart disease, lung disease (including asthma) or other chronic diseases that require regular medical follow-up such as Diabetes mellitus, kidney disease and others.

- Any one who works in a workshop or similar facility not only to protect them against the flu because of the large potential exposure, but also to protect someone they work with who may have other serious medical problems.
- People living in a group home (for the same reasons as outlined for those working in a workshop).

The following recommendation has also been made which would then include nearly everyone:

- Any person who wants to reduce the likelihood of becoming ill with influenza should get the flu shot.

It is also important for families and caregivers to consider the flu shot. Some of our patients are in the high-risk category because of other health problems (heart disease, lung disease, etc). It is very important for those who care for them to avoid giving them the flu. Therefore, nurses, physicians, families, care-providers, direct care staff, and anyone else who has regular contact with our patients should consider the flu shot.

Who shouldn't get the flu shot

- People who have a severe allergy to eggs or other components of the flu vaccine. (An upset stomach, diarrhea or other gastrointestinal complaint from eating eggs does not prevent a person from getting the flu shot).

- People with an acute febrile illness (fever) should not be vaccinated until their symptoms have resolved.

What should you do

- Review these recommendations.
- Call if you have questions.

If the flu shot is right for you:

- Call our office or stop at your pharmacy, another doctor's office or any of the many places you can get the flu shot.
- Roll up you sleeve.
- Stay healthy.

Orthopedics Study

Orthopedic problems

Numerous orthopedic abnormalities are associated with Down syndrome. Common problems such as subluxation and dislocation of the cervical (neck) spine (including atlanto-axial instability), hip, and patella (knee cap) may cause significant health problems. Generalized ligamentous laxity is the underlying cause of these manifestations. Little has been reported about the natural history of orthopedic disorders associated with Down syndrome in later life. The objective of this study is to determine the prevalence of cervical spine instability, precocious cervical degeneration, degenerative scoliosis, spondylolithesis (slippage of vertebrae), and appendicular abnormalities of the shoulder, hip, and patella in a population of adults with Down syndrome. Approximately 200 adults with Down syndrome (age 18 and older) are being sought for this survey.

Why is this study important to the people we see at the Adult Down Syndrome Center?

We became interested in this question when we started to see several people with instability of the neck that resulted in pressure on the spinal cord that resulted in neurologic impairment. We had previously been recommending that all our patients receive one lateral neck x-ray series in adulthood (once they stopped growing). However, as we started to see more people with neck problems, we knew we needed more information.

Who is conducting the study?

Dr. Steve Mardjetko, an orthopedic surgeon who specializes in spine problems, has seen several of our patients and expressed interest in further evaluating orthopedic problems of persons with Down syndrome as they age. Dr. Mardjetko and the Adult Down Syndrome Center will be conducting this study.

What does the study consist of?

Individuals will undergo a complete orthopedic, neurologic, and radiographic (x-ray) assessment. The prevalence of orthopedic abnormalities due to generalized ligamentous laxity will be determined.

Where will it be done?

The exams and x-rays will be done at no charge at Dr. Mardjetko's office which is in the Parkside Building, next door to Lutheran General Hospital.

Institutional Review Board Approval

The Institutional Review Board of Lutheran General Hospital has approved this study.

How do I get further information or sign up?

Contact Leonard Basobas (in Dr. Mardjetko's office) at 847-375-3000, ext 3071.

Grief Following a Death Loss

We recently purchased several copies of a pamphlet published by The ARC. "Mental Retardation and Grief following a Death Loss" is a short, easy-to-read pamphlet with lots of great suggestions. The author is Charlene Luchterhand, MSSW.

I encourage everyone to take a moment and look through it or check it out of the Resource Center for a more thorough review. The author did a fine job of summarizing the important issues in a concise fashion, so I won't try to shorten it any more for our newsletter but will mention a few important points.

The grieving process, particularly for our patients may be delayed. It is not uncommon for us to see a person with Down syndrome do well for 6 months or more and then to express their grief.

Sometimes a person will do fine for a long time and then another loss event will occur that triggers the grief response. For example, a very significant person (such as a parent) will

die and our patient seems to do fine. Then months or sometimes years later a less significant loss will occur (a person far removed from our patient, the turtle at the group home, etc) and then our patient expresses grief. We have seen several such instances in which suddenly several years later the person will start talking about the loss of the significant person in his life.

The pamphlet offers possible explanations for delayed grieving:

- The person may not have healed from the loss when it occurred.
- The person's network of family and friends may be small and talking about the deceased loved one may help the person feel connected to the loved one through memories.

In addition, I have often wondered about the ability of many of our patients to comprehend the concept of time. Sometimes in describing the death of a family member a patient will talk as if it happened in the last few weeks when it actually happened many years before. We have seen this difficulty with time around other issues as well.

How to help the grieving person

Ms. Luchterland offers the following:

- Be with the person.
- Talk about the death and the person who died.
- Share feelings.
- Encourage the person to attend the visitation/wake and the funeral or memorial service.
- Try to prevent other losses. (Obviously we do not have control over many losses in our

lives. It is recommended to avoid or delay changes or losses, if possible, such as moving, job changes, etc).

- Allow the person to make choices (about how they need to grieve).

She also offers the following when teaching about death:

- Use simple words and avoid words that have more than one meaning (e.g. fell asleep)
- Teach by using examples in everyday life (such as the death of an animal or a famous person).
- Use many examples over time.
- Allow the person to see how you deal with losses in your life.
- Allow him to show emotion.
- Encourage questions.
- Talk about stages of life.
- Identify someone who can lead a class or group to talk about death and grief.
- Describe what is good about death (no longer suffering; after-life if part of his religious beliefs).
- Help the person feel safe now.
- Provide hope.

Sometimes grief goes on for a prolonged time, severely interrupts a person's life and can become part of a depression. It is imperative to try to help the person work through his grief as outlined here, but if the grief becomes prolonged and appears to be more than just a grief reaction, further assessment and treatment may be necessary.

Copies of the booklet can be borrowed from our Resource Center or can be ordered from The Arc of the

United States, 500 East Border Street,
Suite 300, Arlington, Texas, 76010.
817-261-6003 or <http://TheArc.org/>

A Tumor Profile in Down Syndrome

An article in American Journal of Medical Genetics 78:207-216 (1998) by Satge, et al described a review of cancers in people with Down syndrome.

Many people are aware that leukemia is more common in people with Down syndrome primarily in children, especially in infants.

It is interesting to note that “solid tumors” (tumors other than leukemia) are generally less common. Particularly noted to be less common were certain tumors of the kidney, nervous system and skin.

However, some of the solid tumors are more common in people with Down syndrome. These include lymphoma, gonadal (especially testicular) tumors, “extragonadal germ cell tumors” (tumors not in the testicle or ovary that have cells generally seen during our fetal developmental) and possibly a few other types.

Some of the types seen more commonly tend to be seen particularly during fetal development in people with Down syndrome (leukemia and testicular germ cell tumors) and some tend to be seen in infants (leukemia and lymphoma).

For our patients, review of this article has supported our efforts to make

screening for testicular cancer an important step in the physical exam. Despite resistance from some patients to this part of the exam, it obviously remains necessary. It also supports checking for lymph nodes (to evaluate for lymphoma) which is a standard part of the physical exam.

Most of the rest of the increase in tumors is seen during fetal development or in infancy and is not an issue for our adult patients. As far as those thought to be less common, we will continue to monitor as we normally would until there is more evidence of the reduced need to screen.

The Old Hooper

If my legs cannot move
I will wiggle my toes
Till they learn
To do intricate dances.

Lillian Morrison