

## Newsletter Summer 1998

Editor: Brian Chicoine, MD

### Perspectives

I often try to put myself in the shoes of our patients to help me understand them better (or as Atticus Finch says in my favorite book, To Kill a Mockingbird, "wear their skin for awhile"). My perspective is similar to our patients on some issues. However, there are some differences that make it difficult for me to completely understand a patient's perspective and there are often communication issues that cause me to only be able to speculate about his perspective.

I recently read The Road to Daybreak, by Henri J. M. Nouwen. Daybreak is an L'Arche facility in Toronto. L'Arche is an organization of residential facilities in which persons without intellectual disabilities live together with people with intellectual disabilities. This particular book is about his life journey to leave his career as a teacher and writer and go to live at Daybreak.

I find his surmise of the perspective of a person with an intellectual disability interesting and thought provoking. (He does use some older terminology, but I did not change it.)

"...Jean started to speak about Eric, a severely handicapped 18 year old who had recently died. He mentioned Eric's deep sensitivity. Eric could not speak, walk, or feed himself, but when

tension arose between assistants in the house, he banged his head against a wall; and when peace and harmony prevailed, he was joyful and cooperative. 'The handicapped often tell us the truth, whether we want to know it or not'; Jean remarked, and added with a smile, 'It is not always easy to have such a barometer in your house.'... often they are capable of unmasking our impatience, irritation, jealousy and lack of interest and making us honest with ourselves.... many mentally handicapped people experience themselves as a disappointment to their parents, a burden for their families, a nuisance to their friends. To believe that anyone really cares and really loves them is difficult. Their heart registers with extreme sensitivity what is real care and what is false, what is true affection, and what are just empty words. Thus, they often reveal to us our own hypocrisies and invite us always to greater sincerity and purer love."

We have heard families observe many times that their family member with Down syndrome is sensitive to events happening around them (even when the event does not directly concern them)-such as when two people are arguing within ear shot about something that isn't about the person with Down syndrome but the person with Down syndrome gets upset about the arguing. Sort of like the patient in the hospital who is already feeling vulnerable and hears someone laugh at the nursing station and assumes (or wonders) if

they are laughing about him. Even that little misunderstanding can alter his perception of the whole hospitalization or care.

How much worse when one does not have or is limited in ability to communicate this uneasy feeling or to straighten out the confusion.

I suspect (and am quite certain) that the difference in level of development can cause someone with Down syndrome to have a different perspective on events than someone who does not have an intellectual disability. This is the same issue as having a different perspective because of different education, different life experiences, and different levels of well-being.

Even well intentioned actions may be misinterpreted. Whenever I think of "perspective issues", I recall an episode I had with one of our children a few years back. As I was driving home one snowy evening, I phoned home to discover a baby sitter with two of the girls and the other at her piano lesson. I calculated that I would arrive in the neighborhood about the time her lesson ended and told the sitter I would pick my daughter up at the end of her lesson to save her a three block walk in the snow. Unknown to me, my wife had arranged with the sitter to go to the end of the block and watch our daughter walk home safely. When I picked her up, she was angry with me (and I was being a nice guy-or so I thought). This was to have been a six year old's much-desired first adventure into greater independence.

Good intention, wrong perspective.

I often wonder how many times a day a person with Down syndrome reacts to or interprets events going on around him or actions directed towards him in a way that others don't understand because his response is from a perspective different from that of the other person. The person with Down syndrome may

have a physical pain or psychological stressor that is unrecognized by the other person. He may have had something happen several hours before that causes him to react in a way we don't expect (who of us has not reacted in such a way to a small thing when in reality it is in response to something else that happened previously). It can be very difficult to understand someone else's perspective. However, we will keep trying to put that into the assessment and the treatment for our patients. I am quite sure we don't have all the answers at the Adult Down Syndrome Center. However, it certainly is fascinating learning from and with families, staff, and most of all, persons with Down syndrome.

## **Clinic Publications**

"Overweight Prevalence in Persons with Down Syndrome" (Rubin, Rimmer, Chicoine, Braddock and McGuire) was published in the June 1998 edition of Mental Retardation. We found that in our sample of 283 patients for which we had data at the time of this study, we did confirm previous studies and the general sense that persons with Down syndrome are often overweight. 45% of our male patients and 56% of our female patients were overweight. These figures were higher than for the general population (33% of men and 36% of women). Although not statistically significant, we did find a trend towards the persons who lived at home being heavier.

We did not study the cause for this difference in this study. However, in a previous study we had found that adults with Down syndrome who had greater opportunity for social activities were more likely to be closer to their ideal body weight. Previous studies by other investigators did find that people with intellectual disabilities that live in group homes often have greater involvement in community skills training. Perhaps greater opportunity for social activities played a role in the trend we found in this most recent study.

I suspect you have gathered by now, if you are a regular reader of the newsletter, that we are big proponents of activity. Exercise and activity burn calories, reduce stress and improve the sense of well-being. We encourage turning off the TV and getting out and doing something (sounds like my mother when I was a kid).

## **Good-bye Dr. Gratigny**

As was previously reported, Dr. Gratigny and her family decided to move to Littleton, Colorado. Dr. Gratigny saw her last patients here in early June and has now moved. Dr. Chicoine will provide care for her patients.

Dr. Gratigny has had a great deal of contact with The Eleanor Roosevelt Institute about starting a clinic for adults with Down syndrome in Denver. Our best to her.

## **Clinic Presentations**

### **IASSID**

Dr. Chicoine participated in the International Association for Scientific Study of Intellectual Disabilities (IASSID) Special Research Interest Group on Health conference (what a mouthful) in Manchester, England in early June.

1999 is the World Health Organization "Year of Aging". IASSID) has been asked to develop a position paper for the World Health Organization on aging in persons with intellectual disabilities and Dr. Chicoine is a member of the steering committee on medical issues.

### **NDSS**

Dr. Chicoine also presented at the National Down Syndrome Society annual meeting in Delevan, Wisconsin in July on "Promoting Health in Adults with Down Syndrome".

## **From Your Head to Your Toes**

Jeannine Hogg, (Medical Student from Chicago Medical School)

What is the largest organ in your body? What is the one thing that everybody has problems with from time to time? You are probably thinking of all the important organs IN the body like the heart, the liver, the brain and the thyroid gland that can cause serious problems and make people very sick. But that is not what I am talking about. I am referring to something more obvious, something right on the tip of your nose (and your cheeks, your elbows and your knees). I am referring to the SKIN. The skin covers every part of your body and is the largest organ of the body and is, therefore, one of the most important. It protects all of the organs on the inside from the elements. It helps to keep us warm and helps to cool us off. However, the skin can only do its job best when it is healthy. There are many different issues in skin care in persons with Down syndrome. Here is a look at some of the skin care issues and problems that can come up and ways to treat and prevent them from happening in the first place.

If you start at the top... your head, you will find some conditions of the scalp of which to be mindful. Alopecia is a condition that is related to a variety of genetic factors in which a person loses the hair on their head and often other parts of their body. This is a condition that can spontaneously occur and can spontaneously resolve. There is no real treatment for the condition. Another condition, seborrheic dermatitis (better known as dandruff) can often be treated or controlled. Oftentimes this dry, scaly, and flaky skin on the scalp can be caused by a fungal infection and may respond to an anti-dandruff shampoo, a tar-based shampoo, or the prescription anti-fungal shampoo, Nizoral. This problem can often be managed (although generally not cured) by regular use of these shampoos.

As you travel further down the body, another condition, that many people with Down syndrome have, is folliculitis. This condition, which is an infection of the hair follicles, usually presents as a itchy rash with small bumps (papules) which on some people appear reddish. The rash is most common on the upper back, chest and shoulders. This infection can be bacterial or fungal in nature. The most important step in keeping this skin problem under control is to keep the affected area clean and dry. It is also important for the patient not to scratch the area since this can cause further infection and problems. Your doctor will decide if medication (such as an antibiotic or antifungal) is necessary.

Something to consider that can be a problem all over the body is xeroderma or xerosis, which are clinical names for dry skin. Our skin functions best when it is healthy, moisturized and intact. This allows the skin to perform its vital functions of keeping the elements out, regulating our body temperature and protecting our muscles and organs. Xerosis, or dry skin, can cause significant discomfort including itching and skin cracking which can lead to the possibility of infection. It is a good idea to make sure that moisturizing and conditioning of the skin is part of the daily routine. Make sure the skin is cleansed daily, avoiding extremely hot temperatures of water which can contribute to drying out natural oils. After every shower or bath, apply a moisturizing lotion like Lubriderm or baby oil (Johnson's now makes a very rich, non-greasy gel) all over the body, paying particular attention to the areas that need extra moisture such as the elbows and knees. Sometimes several applications are necessary on the particularly dry areas.

Finally, as you reach the bottom of the body, your feet, there is a problem that is particularly prevalent in persons with Down syndrome. This is the problem of fungal infections of the skin of the feet or the toenails. Tinea pedis, (athlete's foot) the infection of the skin of the feet, can

present as dry, scaling or flaking areas with a whitish appearance on the feet or between the toes. Sometimes the infection can be moist between the toes.

Onychomycosis, fungal infection of the nails, causes the nails to appear yellowish, thickened and hard and may make it difficult to cut or to take care of properly. Tinea pedis usually responds to washing and drying two to three times a day followed by placing anti-fungal cream on the skin. Sometimes an oral medication is necessary to treat difficult cases. Onychomycosis generally requires oral medications. If it is not bothering the individual (which it often does not other than to be a cosmetic issue), then regular trimming may be all that is needed. If the nails are particularly difficult to cut, it may be necessary to consult regularly with a podiatrist. Prevention of these problems should include daily cleaning and drying of the feet including between the toes.

These skin problems can usually be managed if regular care is given to good cleaning, drying and moisturizing. In addition, regular checking of the feet for small irritations and prompt treatment can help prevent them from becoming big irritations. The skin is the biggest organ and taking care of yours is an important job.

## **Resource Center**

The Adult Down Syndrome Center has received two generous grants to help us develop a resource center. The Twentieth Century Juniors Foundation of Park Ridge selected the Center to be the main recipient of their annual fundraising efforts, which included a fashion show in November 1997, attended by approximately 1000 people. We received over \$39,000 from all their hard work and generosity. In addition, we received \$17,500 from the Goldberg Foundation towards the purchase of computer equipment for the Center. Computer equipment, furniture, books, tapes and other resource materials have

been ordered. Further details about the resource center will be in the next newsletter. We are very excited about these generous grants and donations and are looking forward to expanding the education component of our mission.

### **Michael Johnson's Paintings**

We encourage you to come to the Center and look at Michael Johnson's paintings that are on display. Michael is a young man with Down syndrome who lives in Evanston and is a painter. He has some remarkable oil paintings on display (that can be purchased). They brighten up our day at the Center and we think you will find them as remarkable as we do.

### **Research Project**

We are participating in a research project with Northwestern University. Please see the attached letter. We are trying to find out more information about Down syndrome and Alzheimer's disease. Several years ago researchers did autopsies on persons with Down syndrome who had died from a variety of causes. All of the people who had died over the age of 35 had changes in the brain similar to the changes seen in the brains of people (without Down syndrome) who had died from Alzheimer's disease.

Unfortunately, many concluded that all people with Down syndrome over the age 35 got clinical Alzheimer's disease. We can only positively conclude that the exact incidence of Alzheimer's disease in persons with Down syndrome is not known at this time. Based on our experience at this point, we suspect that the incidence may not be any greater but that when it does occur, it occurs at a younger age (mid to late 40's, 50's and 60's vs. 60's, 70's and 80's in the general population). We have also seen our patients who develop Alzheimer's disease decline more rapidly than person's in the general population.

The present study that is addressed in the letter will help us better understand the role of ApoE4 protein in Alzheimer's disease in persons with Down syndrome. This gene has been found to put people in the general population at greater risk for Alzheimer's disease. In addition, in a study referred to as the "nun" study (because the subjects are a group of nuns), it was found that those that had the greatest level of proficiency with the written word when they entered the convent years before, were the least likely to develop Alzheimer's disease. Level of functioning prior to the development of Alzheimer's disease may be a risk factor for developing Alzheimer's disease.

The data on ApoE4 protein as a risk factor for Alzheimer's disease in persons with Down syndrome has been studied but so far the studies have had mixed results.

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 this area to help us to optimize the health of our patients.

### **Upcoming newsletters**

In future newsletters, we will address issues of osteoporosis and discuss our resource center. If you have topics that you would like addressed, please feel free to contact us.

We also invite persons with Down syndrome, families and care providers to submit articles, letters, etc for publication in future issues.