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Veronica White seizes the day

By John Simpson and Mike Harmer

hat kind of person can live the golden rule to the point that it brings a chaplain to tears? The kind of person who receives devastating news about her health, undergoes radiation, experiences a stroke, hemorrhage, and paralysis, and then welcomes readers to her blog with the words, "GOD, I LOVE LIFE. Every morning I wake up, open my eyes and say, ALL RIGHT!! Another day and I'm still here!"

These may seem like extraordinary accomplishments—a lifetime's worth for just about anyone—but they only represent a small part of what Veronica White has achieved in just the last few years.

The source of Veronica's strength lies in the devastating facts of her medical history. They can be recounted with clinical detachment. Ten years ago, in the summer after Grade 6, a CT scan revealed that she had Arteriovenous Malformation (AVM) in the left side of her brain, a rare condition that can be described as an "aneurysm waiting to happen." Radiation treatment designed to help improve her condition did just the opposite it triggered a progressive stroke and Veronica was forced to use a full leg brace to compensate for severe weakness on the right side of her body.

It was then that Veronica first



Veronica White

came to Erinoak and embarked upon the long-lasting relationships with therapists and other professionals who would help her on the journey to turn her life around.

Veronica admits, "When I first went to Erinoak, I wasn't really gung-ho about being there. I hated being disabled. But at Erinoak they actually care, which is different than lots of places."

The people at Erinoak helped her accept her situation and then, as Veronica says, "Things started to improve. I didn't want to start Grade 9 in a wheelchair, so I worked really hard all summer at my physiotherapy at Erinoak and participated in horseback riding and pool (hydrotherapy) programs. It was great to work with
Susan Cannon (Social Worker)
and Jon Greenaway (Transitions
Coordinator) and such an organized
team. They knew just what to do
to help me gain back the most
strength possible, and helped me
first to learn to eat and write with
my left hand, and ultimately get
better to the point where I no longer
needed a leg brace and could lead
a pretty much normal life."

That "normal life" changed dramatically—and for the second time—five years later, following what she now cheekily calls a "totally awesome near-death experience."

In the summer of 2001, Veronica had a major brain hemorrhage. When she woke up at The Hospital for Sick Children in Toronto, she learned from her mother that, "At first, the doctors didn't hold out much hope for me. Then they thought that I'd never regain consciousness. Then they thought that I'd never open my eyes, never get off the ventilator, that I'd never talk, walk, see ..."

"But I beat every single thing they said, and you know how I did it? With people praying for me, my family by my side encouraging me day and night, and my friends visiting me almost every single day in the hospital, how could I not?" Following months of rehabilitation, Veronica once again made her

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Veronica loves life

continued from page 1 way back from a wheelchair to full mobility and learned how to cope with problems in orientation and short-term memory. But as significant as that was, it wasn't her only accomplishment. She created a foundation for AVM and adopted the attitude and drive that characterize her life today.

"... life is to be lived and enjoyed no matter how long or short it is — anyone can make a difference no matter who they are."

"My whole attitude towards life really started to change then," she says. Instead of feeling sorry for myself, I decided that there must be some reason for my survival; that life is to be lived and enjoyed no matter how long or short it is; and that anyone can make a difference no matter who they are. While I was rehabilitating, I helped other kids any way I could, by reading to them or tutoring or just trying to cheer them up. After I got out I decided that someone needed to do something about the lack of research or knowledge of AVM. So I started my own foundation to raise money for research at Sick Kids Hospital and for raising awareness through a program at Toronto Western Hospital."

She redoubled her efforts at St. Thomas Aquinas Catholic Secondary School in Oakville, excelling in the classroom, playing in school bands and ensembles, working with the light and sound crew at school functions, teaching guitar and piano to younger students, helping the school chaplain, and assisting with charitable campaigns. Her commitment was rewarded with a number of scholarships and prizes, including the Terry Fox Humanitarian Award and Erinoak's Diana Thomson Award.

The summer Veronica's high school career finished, she got a triple header of good news. First, she graduated and decided to go on to university. Second, after a two-day hospitalization for surgery, a final angiogram confirmed that Veronica is AVM-free. Third, she revived her relationship with Erinoak through its Independent Living Program at Sheridan College. With a group of new friends who dubbed themselves the Random Misfits, she lived and cooked in residence and attended workshops on how to live independently, going boating and taking public transit to Toronto. Veronica says, "I made some awesome friends, and still keep in touch with all of them. It was a great opportunity for a lot of kids and I wouldn't have been able to survive without it."

Veronica is now majoring in social work at Redeemer University College in Ancaster. She plans to go on to post-graduate studies at Ryerson and a career "working with disabled youth, especially those in not-so-good home situations. My family was 100% behind me but there are a lot of kids whose families see disabilities as a curse." Veronica knows from experience that "they have emotions, drive and goals but some families sometimes don't appreciate that."

But even before her professional career starts, Veronica is already helping people. She has started foundations for AVM, built a website, gives inspirational speeches, and travels to malls and hospital lobbies, fun fairs and charity walks, selling decorative angel ornaments. She has also found time to raise money for Erinoak.

Veronica was the driving force behind Walk Cuz You Can, at St. Thomas Aguinas, her old high school, where \$1,500 was raised. When the money was tallied she decided \$1,000 would go to her AVM Foundation with the remaining \$500 to the victims of Hurricane Katrina. It was an act of generosity that made the school chaplain cry. Walk Cuz You Can is "a huge deal" she says, "because the kids who participate are at the age I was when I went through all this. If I have my way, one day it will be as big as the Terry Fox Run."

Right now Veronica is lifting weights, climbing stairs, and riding the stationary bike every day. The girl who was told she might have to put her life on hold says, "I'm going to graduate with no leg brace and wear high heels if I feel like it, and I'm going to take my diploma in my right hand and wave it and blow kisses to the crowd."

Veronica can be remarkably philosophical for someone so young. "I've changed a lot in the past five years especially. Before the second brain hemorrhage, I saw everything I was going through as a curse. Now I see it as the hugest blessing I've ever received."

With continuing support from her family and help from dedicated people who work at organizations like Erinoak, it appears that there is no challenge too great, no obstacle too high and no chasm too wide to deter Veronica from not just living life, but hugging life for all it's worth and squeezing every ounce of love out of it.

BRIDGET FEWTRELL: Defining leadership

Interviewed by Jeanette Mayer

ice-President, Clinical Services and Strategic Initiatives Bridget Fewtrell is responsible for four major programs with a combined budget of \$25 million, and a staff of 300. Her principle-centred leadership and managerial moxie create a climate in which success is born and enjoyed. Fewtrell radiates positive energy and dedicates her talents and resources to noble purposes, in service to others. Her competence is self-evident. What's revealed in short order is a character rich in integrity, maturity, authenticity and generosity of spirit.

JM: I understand that prior to joining Erinoak in 1999, you worked in the private sector (advertising and marketing, operations) for 15 years. What prompted your interest in social work? BF: My family is very socially-

conscious and from an early age, it was expected that we develop civic-mindedness. I intended to do something involving human welfare. However, life takes its dips and turns and I ended up in marketing and advertising, which I absolutely enjoyed. In the back of my mind though, there was always a sense that particular career would not last forever. Several years ago, there were a number of significant events in my life including the death of my Dad and a good friend that happened close together. I took pause and realized that if I wanted to actually do something of more value, I would have to be purposeful about it. I made a conscious decision to stop what I was doing to go back to school, knowing that to move into non-profit or public service I needed



to augment my education. I have undergraduate degrees in political science and social work, and my master's degree is in policy analysis, with a specialty in program design, implementation and evaluation.

JM: What brought you to Erinoak? BF: I was working on a paper that had to do with access to treatment issues for persons with disabilities. I knew about Erinoak and asked Mary King-Lyons (now Vice-President, Clinical Services) if I could meet with and talk to her about the organization. I explained to her what I was researching and she welcomed me with open arms. The next thing you know, I was here for placement and never really left. I continued on through my master's and did some consulting work. When I graduated, President & CEO Linda Rothney offered me a full-time position as a (.5) Coordinator, Continuous Quality Improvement/Special Projects and (.5) Social Worker and I couldn't have been more pleased.

JM: What areas are you responsible for?

BF: Currently, I oversee four programs; Central West Preschool

Autism Services, Central West School Support Program-Autism Spectrum Disorder, Halton-Peel Preschool Speech and Language Program and Central West Infant Hearing Program. Those are my clinical duties but as well, I'm responsible for assisting with strategic initiatives. I would say that the clinical directorship takes up about half of my time and strategic initiatives, the other half. JM: Tell me about some strategic

initiatives you've directed.

BF: I've been privileged to have led the organization through what will now be our third round of accreditation, and implementation of the clinical modules of our new Meditech information system. Of course, all of these undertakings involved many of my very talented and supportive colleagues. I was fortunate to get support to conduct a feasibility study around our intake system that eventually became the centralized intake project, and was also involved in the beginning phases of the Brief Intervention Clinic. I have overseen implementation of our last three program additions, all of which span Ontario's Central West Region and right now, I'm working with the President and CEO and Board subcommittee to support the Erinoak redevelopment project.

JM: What is the greatest challenge facing Erinoak?

BF: One of the major challenges facing all children's treatment centres is the need for a global budget and planned yearly funding increases. We work in a very resource-constrained environment and Erinoak has done an admirable job of planning for and developing infrastructure to

Please see FEWTRELL on page 6



2005 Client Satisfaction Survey

hree years ago, Erinoak, KidsAbility, and the NRC+Picker Group Canada collaborated on a survey tool that evaluates services from the client's perspective.

In-depth interviews were conducted with clients and families to determine what was most important to their care experience. In addition, a multidisciplinary team of professionals from all program areas formed a survey task force to provide direction regarding the questionnaire content and format.

The aim of the Client Evaluation of Services Survey was to assess the strengths and areas for improvement in the quality of care and services provided by Erinoak through feedback from its clients. Erinoak is pleased to share a summary of the results of the survey's second wave. The questionnaire contained almost 40 core questions and was divided into the following sections:

- Access to Care: Are we providing good access to care?
- Meeting Client Needs: Are we meeting the client's and family's needs?
- Family-Centred Care: Are we family-centred in our care?
- Information and Education:

 Do we provide the information and education that is needed when needed?
- **Support:** Are we providing the required support while waiting for services and the needed community linkage?

Telephone interviews were conducted during August and September 2005 with a random sample of 1,439 clients who The questions presented below are areas in which Erinoak does well. Bars indicate items with the highest "percent positive" score.

Items ranked in descending order by current score	% Positive Score	
Are your child and your family treated with respect?	Always	96.2%
Are you provided with information about your child's progress in a way you can understand?	Yes	93.7%
Do the staff provide a caring atmosphere?	Always	92.7%
Are you comfortable expressing your opinions even if they are different than those of your therapist or doctor?	Yes	89.6%
Do the staff work well with your child?	Always	88.1%
Are you involved in your child's treatment as much as you would like to be?	Yes	85.7%
Did you have any difficulty transitioning from one type of service to another (e.g. from preschool to school age, adolescence to adulthood)?	No	85.2%
Can you get this information in writing if you want it?	Always	83.1%
Do the staff work well with your family?	Always	82.5%
Do the staff provide enough time to talk so that you do not feel rushed?	Always	81.4%
	SOU	IRCE: NRC+Picker Car

received services in the last six months. The final sample yielded 601 interviews; 100 in Multidisciplinary Preschool, 150 in Multidisciplinary School Age, 51 in Preschool Autism Services, 50 in Infant Hearing Program, 200 in Halton and Peel Preschool Speech and Language, and 50 among discharged clients. Overall, the response rate was 60.4%. The refusal rate was 11.2%.

KEY FINDINGS

• Likelihood to recommend your organization
Eighty-six percent (85.5%) of the clients responded positively about the likelihood to recommend Erinoak to another family member or a friend needing these types of services.

- Overall quality of care
 Ninety percent (90.3%) of the
 clients rated overall quality of
 care and services as excellent
 (54.8%) and good (35.5%).
- Strengths
 Questions with the highest
 "percent positive" scores can be
 considered strengths relative
 to the other questions asked
 (see bar graph above).

AREAS FOR IMPROVEMENT

The following questions received the lowest "percent positive" ratings:

- Have you been informed of Erinoak's compliments and complaints process? (21.3%)
- How much information or support did you receive to help you while waiting for services to begin? (30.4%)

Please see SURVEY on next page

¹ Wave 1 took place in 2003.

Drama group takes centre stage

I t felt like a night at the Oscars for Erinoak's Drama Facilitator Danielle Strnad, drama participant Payal Gupta, and a small but ardent group of supporters. For the second year in a row, Erinoak's drama group had been nominated for one of the Mississauga Arts Council's prestigious awards in the category of Emerging Performing Arts Group, and this time they won.

With one small weekly class, the program originated in 1999 to enable participants to explore creative expression through drama, guided storytelling, pantomime, creative movement, and the development of original scripts. Led by the vivacious and ever-encouraging Danielle, the group received support from the Trillium Foundation that has allowed it to grow to its present level of activity, encompassing two weekly classes, an annual production for the community, multi-arts summer day camps and themeoriented drama activity days.

Thanks again to Trillium, the Drama Department of Cawthra Park High School for the



Erinoak applauds its award-winning players: (from l to r) Payal Gupta (seated), Renee Ellis, Jenny Noble, Danny Buffett (staff), Catherine Vertolli, Mark Catalano, Danielle Strnad (facilitator), Adrian Nandlal, Meagan Pouge (volunteer), Scott MacCattie, and Christina Laurenza (volunteer).

Performing Arts and Erinoak's Music Therapist Sarah Britnell have partnered to establish a bell choir (under Sarah's direction) and allow student input into all aspects of the program.

The recognition of the community was moving and encouraging. As

Payal and Danielle acknowledged in their joint acceptance speech, it was a tribute both to the faith the Trillium Foundation has displayed, and the enthusiastic participation of all the Erinoak Players since 1999, whose spirit informs this year's group. Bravo!

Survey provides invaluable client feedback

Continued from previous page

Questions that achieve low positive scores are given priority in terms of further investigation of problem areas and in identifying improvement initiatives.

OPEN-ENDED QUESTIONS

The survey contained two openended questions: "If there was one thing you could change about Erinoak services, what would it be?" and "Are there any additional comments you would like to make about the services you receive from Erinoak or through one of its partners?" These comments were themed.

- One thing clients would change about Erinoak services
 The two most frequently mentioned changes that clients would like to see made to Erinoak services concerned:
 - The length of time or frequency with which services are provided (16%)
 - Processing time/shorter waiting lists (20%)
- Additional comments about services received

At the end of the interview, clients were given the opportunity to make any additional comments concerning the services they receive from Erinoak or its partners. The two most frequently mentioned types of comments concerned:

- Good service/thank you (35%)
- Quality of therapists/service providers (21%)

For more information, please contact Martha Baker, Coordinator, Quality Management at 905-828-3258 or mbaker@erinoak.org. **



Fewtrell radiates positive energy

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better serve clients and families. However, that is difficult when funding is flatlined because we can't resource properly year over year. We really need to move towards a global budget and develop with the Ministry of Children and Youth Services proper resourcing for the organization in the same manner that one sees with hospitals so that we can engage in long-term planning. Organizations like Erinoak are their people and if we don't have appropriate infrastructure and competitive salaries to attract and retain the kind of professionals that will allow us to provide quality service, that erodes the base of the organization. Linda Rothney is an adept advocate for Erinoak, and we'll get there, but it's certainly a challenge.

JM: You've clearly seen many changes (at Erinoak) in the last seven years. Any predictions of what the future might hold?

BF: Erinoak is on a wonderful track. It's a successful organization peopled by dedicated professionals. I predict that what we have now will just become more enriched and entrenched over time. I see us in our new facility, well-resourced and with the space required to continue to offer innovative, integrated services for children and their families.

JM: What is Erinoak's greatest strength?

BF: Definitely its people. I think that one of Erinoak's great successes as it has grown is that it has retained its culture and its ability to attract and retain professionals of stellar qualification and incredible dedication to our clients and families. That, above all else, is what makes Erinoak a great organization.

"Leadership is hard to define, but I believe it is an ability to create a vision of the future and imbue others with a sense of that vision to the point where they'll come along for the ride."

JM: How would your coworkers/colleagues describe you?

BF: I think people who work with me would say that I'm a fair and equitable person ... that I listen carefully when people speak with me. I'm blessed in terms of my CEO, my colleagues, and those I have reporting to me. They are such talented individuals and are very knowledgeable about the areas they oversee. It's truly important to hire great people and to take their advice. I set high standards for myself and for them, and I hold them accountable for reaching the goals that we've set together. At the same time, I think they'd tell you that I'm a good person to work with. I take my job seriously, but I don't take myself too seriously. JM: Has working at Erinoak

JM: Has working at Erinoak changed you?

BF: I don't think it has changed me in so much as it's provided me with an environment in which I can operate from an authentic place in myself. In my earlier career I loved what I did and was passionate about it, but I always had some dissonance around the relative worth of what I was doing. Erinoak allows me to work in harmony with my belief system, my principles and my values.

JM: How do you define leadership?

BF: Leadership is hard to define,
but I believe it is an ability to

create a vision of the future and imbue others with a sense of that vision to the point where they'll come along for the ride. Leadership also entails seeing the latent possibilities within others, and assisting them in developing those possibilities. I think good leadership requires incredible integrity because leaders ask people to go on a journey that sometimes entails risk, and whose outcomes are not always clear to all participants at the outset. So, good leaders have to engender trust. To do so, one has to be a person of high integrity.

JM: Looking back on your career, is there one particular achievement that stands out? What are you proudest of?

BF: I believe achievements belong to the collective. For every achievement that one person can cite in their life, be it their personal or professional life, myriad people have enabled that at some level. It's very easy to see in the workplace. One person oversees a certain area or project but it requires the strength, the capability, the buy-in and the hard work of the collective to bring that project to completion. I think my greatest achievement has been remaining passionate about what I do, and I hope it shows. Living my life that way is, in my eyes, an achievement. **

Volunteer-extraordinaire honoured

rinoak joins the Ontario
Ministry of Citizenship and
Immigration in celebrating
Gwen Carlson as a recipient of the
2005 Ontario Volunteer Award in
recognition of 34 years of exemplary
service to Erinoak's children
and families.

Her contributions include active Board membership for over 24 years, hiring Erinoak's first Executive Director Diana Thomson, current President and CEO Linda Rothney, and social worker Mary King-Lyons (now Vice-President, Clinical Services). Gwen kept a watchful eye on the building construction of the South Millway site, promoted the Respite Camp, has had input into all accreditation processes, and advocates staunchly on Erinoak's behalf for major funds. The list goes on. No task is too great or too small for the seemingly unstoppable Gwen Carlson who also volunteers tirelessly for organiza-



(From l to r) Mary Ross, Coordinator, Community Relations & Volunteer Services, honoree Gwen Carlson and Rachele Dabraio, Director, Ontario Honours and Awards Secretariat.

tions such as the Streetsville Lions Club, Canadian Red Cross, and VON, among others.

Says Gwen, "Volunteering gives

back to me more than I can ever give." The entire Erinoak community thanks Gwen for her extraordinary dedication.

They shoot! They score ... a \$95,000 recreation grant!

rinoak's recreation program, a good news story in itself, is celebrating a two-year grant from the Ministry of Health Promotion's Communities in Action Fund. Clearly, success breeds success, as Erinoak takes on a new and more vigorous part in the provincial government's ACTIVE2010 strategy, aimed at increasing physical activity and sports participation.

The grant enables Erinoak to provide more sport and recreation opportunities for children and youth with special needs who live in Peel and Halton. Whether clients are team players, or prefer more individual active pursuit, Erinoak will design programs to promote their health, wellness and fun.

Those who participate will enjoy new friendships, improved health, self-esteem, self-confidence and independence, while developing lifelong leisure skills in a context of community involvement. Some of the activities to be offered, in partnership with local agencies, include family skating, weightlifting, bocce, and biking.

Adrienne Boyes, Manager, Family Support Services and Deanne Clipperton, Therapeutic Recreation Specialist are on the podium for their winning efforts. Congratulations! *



Proudly presents its first Indian theatrical production



September 9, 2006 at Markham Theatre

An inspirational drama, about the turbulent life of a boy who journeys through disability, despair, loss, encouragement, achievement and ultimate success.

Aum Productions is a non-profit organization formed by volunteers that share a passion to promote cultural awareness through arts, music and dance.

Proceeds will benefit Erinoak.

For further information, please visit www.ravi-play.ca or contact Ramesh Mistry at 905-824-8824.



Diana Thomson Scholarship Award

n 1998, the Board of Directors established an award available to Erinoak clients pursuing post-secondary education. It honours former Executive Director Diana Thomson, for her dedication and devoted service to young people with special needs. The scholarship is intended to encourage students with physical disabilities to develop

independence and personal advocacy by pursuing academic goals at the post-secondary level (i.e. university, community college, or other scholastic centres).

An award of \$500 will be presented to the worthy recipient at the Annual General Meeting on June 28, 2006. The application deadline is May 1, 2006. For a

form, visit reception (at each site) or www.erinoak.org and select *resources*. To have one mailed, call 905-820-7111.

For further information regarding scholarships and bursaries, please contact Transitions Coordinator Jon Greenaway at 905-491-4361 or jgreenaway@erinoak.org. **

Family Focus

Grandparents' Workshop (For aunts and uncles too)

Gain a better understanding of how a disability impacts a child and his/her family.

Saturday, April 8

8:45 AM-12:30 PM 2277 South Millway, Mississauga To register, contact **Linda Sutcliffe** at **905-491-4359**

Teen Dance

Friday, May 12

7-10 PM • \$5 at the door Meadowvale Community Centre, 6655 Glen Erin Drive, Mississauga RSVP to **Jon Greenaway** at **905-491-4361**

Brothers' and Sisters' Day

An interactive full-day program for brothers and sisters of young people with special needs to learn and share experiences.

Saturday, May 13

at 905-828-3230

10 AM−3 PM • \$10 per person 2277 South Millway, Mississauga To register, contact **Lee Piepgrass**

Teen BBQ

A fun afternoon for clients and their friends, aged 12–22. Enjoy good food, great music, and squirt guns.

Saturday, June 3

Noon-3 PM • \$5 at the door 2277 South Millway, Mississauga RSVP to **Jon Greenaway** at **905-491-4361**

Erinoak Eagles T-ball and Baseball

A terrific league for children of all ages and abilities. Great family fun.

Wednesdays, June to August

6:30-8:30 PM • \$50 registration fee Springfield Baseball Diamond, Mississauga Contact **Alison Clarke** at **905-828-3214**

Family Fun Fair

Games, activities, refreshments and fun for the whole family. Tickets for games and refreshments may be bought on the day.

Saturday, June 10

10 AM-1 PM 2277 South Millway, Mississauga RSVP to **Alison Clarke** at **905-828-3214**

Community Resource Fairs

Network with over 50 agencies and learn about services available in the community for persons with disabilities. Open to all ages.

Halton Showcase 2006

Thursday, April 27 • 2-8 PM
Milton Sports Centre,
605 Santa Maria Blvd., Milton
For information, contact Joanne Basta
at 905-335-3663, ext. 3210

Connections 2006

Saturday, May 6 • 10 AM-3 PM
Location in Peel TBD
For information, contact Matthew
Fleet at 905-755-9157 or
coalition.pwd@sympatico.ca

Save the dates

21st Annual Spring Gala

Friday, May 5, 2006 La Primavera Banquet Hall, Vaughan

14th Annual Golf Classic

Friday, June 16, 2006 Lionhead Golf & Country Club, Brampton For information and registration forms, visit www.erinoak.org and click on What's New. For tickets, contact Ellen Van Doodewaard at 905-828-3215.

