

Volume 15, No. 2 - Spring, 2006



THE COMMUNICATOR

A Publication of the Autism National Committee



Coming in September! Another Outstanding Autcom Conference

The response from AutCom's 2005 Conference in Nashua was so positive that we are returning to Nashua on September 8 - 9, 2006, to pursue *Real Supports for People with Autism*. (We can't promise you beautiful fall New England weather, but we may just get it.)

The Conference begins Friday night, September 8, with Zach Rosetti of Syracuse University leading a panel of people who experience the autism spectrum discussing all aspects of social relationships.

Saturday begins with a keynote presentation by Professor Morton Gernsbacher of the University of Wisconsin at Madison, "The Science of Autism: Beyond the Myths and Misconceptions." The afternoon keynote will be given by Dr. Paula Kluth, author of *You're Going to Love This Kid*.

Also on Saturday there will be an all day workshop led by Pascal Cravedi-Cheng on Facillitated Communication for both beginning and experienced FC users, with the morning program being a more formal teaching session and the afternoon devoted to opportunities for FC users to meet and communicate .

Saturday breakout sessions focus on supports for individuals and their families. Lisa Lieberman, MSW, author of *A Stranger Among Us: Hiring In-Home Support for a Child with Autism Spectrum Disorders or Other Neurological Differences*,

will address the challenges families face in finding and working with support staff in their homes. Dr. Linda Rammler will present "MACS Attack"—her understanding of the Motor, Anxiety, Communication and Sensory issues in autism. Dr. Tom Larsen will speak on how chiropractic and hands-on therapies can ease some of the motor and sensory difficulties people with ASD experience. Dr. Wade Hitzing returns to address behavioral issues in autism. And Michael Dowling and Robert Cutler will describe their work at a high school and how a person with autism can support and inspire troubled youth.

Of course there will be a panel of people with autism telling which supports are real supports and which "supports" are not helpful. And the conference will end with AutCom's Board Members having "The Last Word."

To register for the Fall Conference, go to the AutCom web site, www.autcom.org, and click on *Conference Registration*.

Most people with autism have limited incomes. At AutCom we believe they are the experts on autism, so we need to hear from them. To enable this, we must assist financially. Consider sending a contribution to AutCom for this purpose.

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Making Our Voice Heard

The Autism National Committee was founded in 1990 to protect and advance the human rights and civil rights of all persons with autism, Pervasive Developmental Disorder, and related differences of communication and behavior. In the face of social policies of devaluation, which are expressed in the practices of segregation, medicalization, and aversive conditioning, we assert that all individuals are created equal and endowed with certain inalienable rights, and that among these are life, liberty, and the pursuit of happiness.

As the only autism advocacy organization dedicated to "Social Justice for all Citizens with Autism" one of our goals is to be a strong voice in federal and state legislation and policy. We salute three of our members who have been recently doing just that.

Robert and Barbara Cutler have been spending time with their representatives in support of those with autism. Rob shares a moment with his state senator and representative. Not too far behind is his mother, Barbara Cutler, talking to State Representative Barbara L'Italien who is also the mother of a teenager diagnosed with Asperger syndrome. Rep. L'Italien has filed successful legislation on behalf of children with autism as well as a bill to Ensure the Humane Treatment of Disabled Persons. The latter legislation is stalled in Committee.

Board member Mike Hoover from Colorado recently sat on the floor of the Colorado House of Representatives as a guest of Congressman Tom Plant after he wrote this letter.

I AM INVITING YOU TO COME MEET ME AT THE LEGISLATIVE BREAKFAST SPONSORED BY THE COLORADO DEVELOPMENTAL DISABILITIES COUNCIL. IT STARTS AT 7:30 AM ON MARCH 22 IN FRONT OF THE COURT CHAMBERS. I NEED TO THANK YOU IN PERSON FOR YOUR GOOD WORK HELPING GET FUNDING FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES. I LIKE KNOWING THAT MORE PEOPLE WILL HAVE A CHANCE TO LIVE GOOD LIVES. I LIKE GOING TO THE CAPITOL TO LISTEN TO THINGS THAT ARE HAPPENING. I LIKED THE DAY I GAVE TESTIMONY IN THE COMMITTEE AGAINST THE RUNAWAY BILL. I LIKE KNOWING CITIZENS HAVE A VOICE AFTER THE ELECTIONS TO INFLUENCE POLICY.



Rob Cutler (center) with Massachusetts State Representative Jim Marzilli (left) and State Senator John Havern (right)



Barbara Cutler (R) with Representative L'Italien

I NEED TO SEE HOW THE HOUSE OF REPRESENTATIVES OPERATES WHILE IN SESSION. I NEED TO KNOW IF I CAN JOIN YOU ON THE HOUSE FLOOR ON THE 22ND AFTER THE BREAKFAST. I LIKE BEING ON THE COUNCIL LEGISLATIVE COMMITTEE. I LIKE SPEAKING UP FOR PEOPLE WHO HAVE DISABILITIES. THATS ALL FOR NOW.

MIKE HOOVER

The reasons for founding AutCom persist. What can do you in your part of the country to make a difference?

ASK ROB

Q: What part of the conference are you most looking forward to?

A: OUR ALL DAY FC PROGRAM. I AM LOOKING FORWARD TO SEEING OLD FRIENDS AND COMMUNICATING WITH OTHER PEOPLE WHO TYPE. IT IS GOOD THAT A LOT OF OUR PEOPLE WITH AUTISM WILL BE THERE. WE ALL ENJOY OUR COMPANY. YES. WE DO UNDERSTAND EACH OTHER.

I AM A GOOD MAN WHO USES TYPING TO GET MY WORDS OUT, I WANT TO TYPE SO PEOPLE KNOW I HAVE FEELINGS. I WAS ONCE LOOKED DOWN AT. NOW I AM LOOKED UP TO. WHERE ONCE I WAS QUIET, I NOW HAVE A VOICE. THANK GOD FOR FC. I NOW FEEL BETTER ABOUT MYSELF.

YES WE HAVE FEELINGS. I GET SAD, HAPPY, AND KNOW I CAN FEEL LOVE AND FRIENDSHIP. WE ARE HUMANS WHO WANT TO BE RESPECTED. YES.

Hello!

Hello, my name is Natalie Zagar Williams.

I am a girl, 10 1/2 years old. I have autism.

My favorite things are:

- * Food: Pizza
- * Pet: Cats
- * Family: Margo
- * Drawing
- * Writing & typing
- * Sending e-mails on my computer
- * & everything.

I like to go outside, swim and play soccer.

My kid friends are Maura, Shaylen & Lydia!

* At the Autcom Conference this last year, I sang "Keep The Dream Alive," written by Yolanda Adams.

* I pretend to be a magician, or my favorite detective, Mister Sherlock Hemlock's Mr. Foot, show me the clue! (E-Glad!)

* My favorite Muppet character is Dr. Teeth, the keyboard player, in the band: Dr. Teeth & The Electric Mayhem_/*.



Listen to My Heart

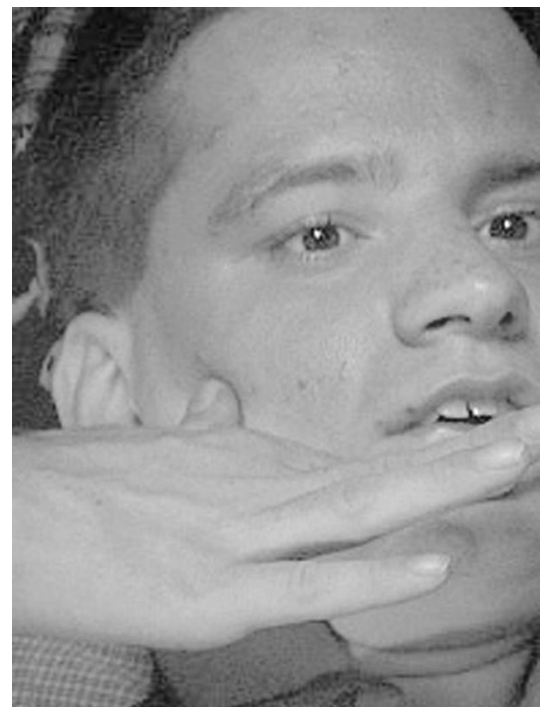
PLEASE FORGIVE THESE CLUMSY WORDS
JUST HEAR ME FROM MY OPEN HEART TO YOURS
THE LANGUAGE OF MY HEART SPEAKS ELOQUENTLY WHILE MY
FINGERS GRAPPLE FOR THE LETTERS ONE AT A TIME.
MY MOUTH HAS NOTHING TO SAY.

HEART LANGUAGE REMEMBERS THE BEGINNING
AND FORSEES THE END
IT HOLDS MY WHOLE LIFE IN ONE SINGLE GLANCE
AND TRIES TO CONVEY EVERYTHING AT ONCE.

WORDS ON THE OTHER HAND BREAK IT ALL UP INTO A
THOUSAND TINY PIECES
WHICH NEVER GO BACK TOGETHER AGAIN.

ROY BEDWARD
APRIL 4, 2006
roybedward@yahoo.com.

I AM ROY BEDWARD AND I TYPE MY WORDS AND POEMS. I LOVE TYPING AND WISH I COULD DO IT ALL THE TIME. I BELIEVE TYPING IS MY ONLY HOPE FOR A LIFE.



MY THREE WORLDS

by Wally Wojtowicz Jr.

(Excerpts from his forthcoming book as presented at the Autcom Conference, September, 2005)

IN MY WORLD, MY BLACK WORLD OF AUTISM, THERE IS ONLY THE SAMENESS OF CONSTANT ORDER AND THE JUSTICE OF NATURE THAT I ACCEPT AND WITNESS. OUR WORLD, I NOTICED, IS CHAOTIC, NOISY, AND EXCEPTIONALLY VIOLENT. HOWEVER, I CAN NOW COPE TO A POINT WITH SOME LEVEL OF ALL OF THIS AS LONG AS I CAN RETREAT, FROM TIME TO TIME, TO MY WORLD OF ORDER AND NATURAL LAW AND ASK APPROPRIATE QUESTIONS ABOUT WHAT I SEE AND HEAR. THE ABILITY TO COMMUNICATE FROM MY WORLD TO YOUR WORLD HAS MADE IT POSSIBLE FOR ME TO WANT TO LIVE IN OUR WORLD AND TO SATISFY MY NEED TO BE AMONG OTHER PEOPLE NO MATTER HOW DIFFERENT WE ARE FROM EACH OTHER.

THE TERM "MY WORLD" MEANS MY MENTAL STATE OF BEING, TOTALLY REDUCED TO A PRIMORDIAL LEVEL ON THE OUTSIDE, AND ON THE INSIDE ELEVATED TO THE BRILLIANT MIND WHO IS TRYING TO ESCAPE TO FREEDOM AND TO THE LIGHT THAT I AM AWARE EXISTS ON THE OUTSIDE OF MY BODY. I LIVED, OR SHOULD I SAY EXISTED, FOR THE BETTER PART OF 25 YEARS IN THIS STATE, THE STATE OF "MY WORLD," THE WORLD OF MY MIND AND OF MY IMAGINATION THAT WAS FUELED BY MISINFORMATION AND MISTRUST.

ON MANY OCCASIONS THE INFORMATION THAT I COLLECTED WAS INCORRECT OR ERRONEOUS BECAUSE IT WAS GATHERED BY WAY OF A FAULTY SENSORY SYSTEM. AS THE INFORMATION WAS FAULTY SO WERE MY CONCLUSIONS OF WHAT I THOUGHT ABOUT THE WORLD THAT EXISTED JUST OUTSIDE OF MY BODY. EACH TIME THAT I WANTED TO ASK A QUESTION ABOUT SOMETHING THAT I DIDN'T UNDERSTAND, I WAS NOT ABLE, AND SO THE PHYSICAL WORLD THAT I LIVED IN WITH YOU GREW MORE DISTANT FROM ME WITH EACH UNANSWERED QUESTION. I POINT THIS OUT TO YOU SO THAT YOU HAVE A VERY CLEAR UNDERSTANDING THAT I ONLY WANTED TO SHARE THE WORLD WITH YOU AS YOUR EQUAL AND NOT AS SOME HAVE

VIEWED—THE NONVERBAL AUTISTIC AS BEING PSYCHOTIC AND UNABLE TO LEARN OR TO BE TAUGHT ANYTHING.

THE TERM "YOUR WORLD" IS THE ANTITHESIS OF "MY WORLD." THERE WAS A SHARP DISTINCTION IN MY MIND BETWEEN THESE TWO TERMS. REALIZING THE DIFFERENCE IN MEANING MEANS THAT I UNDERSTAND THE WORLDS THAT I LIVED IN... IN MY MIND, BEFORE I COULD COMMUNICATE, MY UNDERSTANDING OF YOUR WORLD POINTED TO LOOKING AT PEOPLE AND ALL THAT THEY STOOD FOR AS DOING HARM TO ME AND TO MY WORLD. POINTING THIS OUT NOW IS EASY FOR ME TO DO BECAUSE I NOW CAN REALIZE HOW I VIEWED PEOPLE AS BEING MY ENEMY WITH FEW EXCEPTIONS. AS I LEARNED TO COMMUNICATE WITH PEOPLE, MY RELUCTANCE TO TRUST THEM DIMINISHED. I BECAME AWARE THAT I MIGHT HAVE MISINTERPRETED MUCH OF THE INFORMATION THAT I HAD GATHERED ONCE I WAS ABLE TO ASK QUESTIONS AS A RESULT OF USING FC TO COMMUNICATE.

BEFORE I COULD COMMUNICATE, YOUR WORLD WAS TOO BIG FOR ME TO FULLY COMPREHEND THE NUANCES AND HIDDEN MEANINGS OF YOUR LANGUAGE, BOTH VERBAL AND NONVERBAL, AND THE VAGARIES OF YOUR SOCIAL AND POLITICAL STRUCTURES. REVELING IN MY ABILITIES TO WORK WITH FACTS AND FIGURES AND TO READ BROUGHT ME THE MENTAL INDEPENDENCE THAT I DESPERATELY NEEDED FROM YOUR WORLD'S CHAOS. YET, I MOMENTARILY WOULD ESCAPE MY WORLD AT TIMES HOPING THAT YOU WOULD NOTICE MY INTELLIGENCE AND HELP ME TO REPATRIATE TO YOUR WORLD AFTER MY ABSENCE. THIS WAS NOT TO BE, AND MY MEAGER ATTEMPTS AT PROVING MY MENTAL ABILITIES WOULD NOT BE RECOGNIZED BY ANYONE OTHER THAN MY FAMILY FOR MANY YEARS UNTIL I STARTED TO COMMUNICATE WITH FC. NOW I CAN COMMUNICATE WITH YOU ON YOUR LEVEL OF EXPERTISE, FOR MANY TOPICS THAT I AM INTERESTED IN TALKING ABOUT ARE ALSO

TOPICS THAT INTEREST YOU.

NOT HAVING A COMMUNICATION SYSTEM TO RELY ON TO REACH YOUR WORLD TO ASK CLARIFYING QUESTIONS, I WOULD, MORE OFTEN THAN NOT, ANSWER THE QUESTIONS BY DEDUCING THE ANSWERS FROM THE KNOWLEDGE THAT I DID HAVE. BECAUSE OF THIS, MY ANSWERS OF THESE QUESTIONS TO MYSELF WERE NOT AS ACCURATE AS I NOW KNOW THEY MIGHT HAVE BEEN. ONCE I PLACED THIS INACCURATE INFORMATION IN THE FILING SYSTEM IN MY MIND, YOU COULD NOT CONVINC ME THAT I WAS WRONG. I BELIEVED THAT I WAS CORRECT IN EVERY INSTANCE WHERE I UNKNOWINGLY DEDUCED MY ANSWERS FROM INACCURATE OR INCOMPLETE INFORMATION.

BEGINNING FC AT AGE 25 OPENED DOORS FOR ME THAT WERE CLOSED AS A YOUNGER PERSON. I BECAME ABLE TO UNDO MOST OF THE MISCONCEPTIONS THAT I HAD FORMULATED IN MY MIND ABOUT YOUR WORLD WHEN I COULD ASK QUESTIONS ABOUT WHAT I DIDN'T UNDERSTAND. AS MY UNDERSTANDING OF YOUR WORLD INCREASED, SO DID MY TRUST OF OTHER PEOPLE. THE SHADOWS OF MY FORMER DISTRUST OF OTHERS, UNFORTUNATELY, STILL REMAIN QUIETLY RESIDING IN THE NOOKS AND CRANNIES OF MY CONSCIOUSNESS...

OUT SIDE OF THE BOUNDARIES THAT DELINEATE THESE WORLDS I HAVE LIVED WITH MOST OF MY LIFE THERE EXISTS A THIRD WORLD THAT I NOW RECOGNIZE, UNDERSTAND AND EMBRACE. THIS THIRD WORLD, "OUR WORLD," IS ONE PLACE THAT I NOW FEEL AT EASE WITH, IN MOST RESPECTS, BECAUSE I NOW CAN ENVISION WHAT MY LIFE COULD HAVE BEEN LIKE IF I WEREN'T AT CONSTANT ODDS WITH YOUR WORLD. TO LIVE IN A CONSTANT CONFLICT, LIKE I HAVE FOR MANY YEARS, HAS MADE ME USED TO DIVERGENT LIFE STYLES THAT HAVE KEPT MY WORLD AND YOUR WORLD ON DIFFERENT PATHS. THIS IS WHY I NOW SHARE THE ONE WORLD WITH YOU TO PONDER THE FABULOUS WEALTH OF MANKIND THAT INTRIGUED ME IN THE PAST THAT I COULD NOT ACCESS FROM MY WORLD'S VANTAGE POINT.

OLD IDEAS ABOUT THE AUTISTIC PERSON WILL DISAPPEAR, BUT SHADOWS OF THESE OLD IDEAS WILL REMAIN IN PEOPLE'S MINDS FOR MANY YEARS TO COME. NOW I LOOK TO OTHER PEOPLE BECAUSE I NEED THEIR HELP TO LIVE AND FOR THEIR COMPANIONSHIP. I NOW CAN SEE THE REALITY THAT WE BOTH ARE SHARING. IN OUR WORLD I AM THE HAPPIEST. IN MY WORLD I WAS THE LONELIEST. IN YOUR WORLD I WAS THE MOST FRIGHTENED.

Note: This is a summary of the 9 page paper presented at the conference. If you wish a copy of the whole paper or want to share your questions and/or comments with Wally, contact him at wally1@juno.com

Autism Network International presents Autreat 2006

Autreat is a retreat-style conference run by autistic people, for autistic people and our friends and families. It is an opportunity for autistic people and those with related developmental differences, our friends and supporters to come together, discover and explore autistic connections, and develop advocacy skills, all in an autistic-friendly environment.

Autreat focuses on positive living with autism, NOT on causes, cures, or ways to make us more normal. We have an exciting lineup of presentations on a variety of subjects of interest to the Autistic community, including communication, relationships, daily living aids, travel, effects of prejudice, and more. Autreat has been approved to offer Continuing Education Units through the Center on Human Policy at Syracuse University.

Autreat 2006 will take place on June 26-30 at a small university campus in the Philadelphia, PA, area. The campus has plenty of open space for walking, recreation, and enjoying the outdoors. Lodging is in a residence hall with two to four people per room.

(Continued on next page)

(Autreat continued)

Registration includes a supervised activity program for children and teens under 18. For fee information, registration form, a list of workshops, and further Autreat information, go to ANI's website: <http://www.ani.ac>.

Book Review

By Marna Arnes

With openness. That is how Lisa Lieberman provides the much-needed details of finding, welcoming and including support people for in-home care. So often we parents search, first, for the recipe, and then discover that our life requires improvisation. And what we need for improvisation is a combination of philosophy and practicality. Two things linger for me, after reading the book. Most importantly, Lisa models the personal openness required when including someone new in the day-to-day life of your family. The reader is welcomed into varied and intimate details of the Lieberman-Ackerson household. Though it may seem at first a surprising revelation of family life, it is exactly what allows for an honest beginning to a relationship with support providers and helps to ensure the relationship has staying power.

And as personal as the foundation for the book is, in that you feel you know each member of Lisa's family and could comfortably spend an afternoon with them, the practical details of the search, hiring and employment of support people are the best I've come across anywhere. Lisa provides lists of questions to consider before you begin the search for support people, and more lists of questions to ask prospective employees. Not only is it important to be at the same time honest and respectful in the way you describe the person who needs the support, it is important to require honesty from those you are considering as the support providers in your home. I especially appreciate that Lisa calls on others' experiences with the children and family members who have autism and other neurological differences in order to provide a

range of perspectives. You will find answers to questions you have, whether the person who needs support is a young child, teenager or adult. You'll also be offered ideas you may not have considered, as yet.

The book begins with ideas and questions to consider concerning your family, its culture and needs. The following chapters help you describe the job you are creating, and offer suggestions for ways and places to get the word out. Finally, you are treated to a host of ideas, cautions and practical lists for interviewing, hiring, training and sustaining the work of the people who are working with you and for you. As important as is the beginning, so is the ending. For many reasons, people will leave your employ, and Lisa helps explore how to be as thoughtful about that process as with the hiring process. This book is warm and instructive - a wonderful combination.

A "Stranger" Among Us: Hiring In-Home Support for a Child with Autism Spectrum Disorders or Other Neurological Differences by Lisa Ackerson Lieberman. Autism Asperger Publishing Co., Shawnee Mission, Kansas.

This book is available through the Autcom Bookstore. Go to <http://iod.unh.edu/bookstore.html>

Additional Coming Events

The Facilitated Communication Institute at Syracuse University will be hosting a Summer Institute July 17-21. There will be conference sessions and hands-on workshops for both new and veteran FC users and facilitators. Get information by clicking on this link: <http://suedweb.syr.edu/Summerinstitute2006.htm>

The University of San Diego is presenting it's first annual autism institute: People Moving On from July 10 through 12, 2006. This is a 21st Century approach to understanding and supporting people with Autism and those people who care for and about them. For more information, contact: autisminstitute@sandiego.edu or phone 619-260-7705

PRINCIPLES OF THE AUTISM NATIONAL COMMITTEE

As a member of the Autism National Committee I endorse for all people with autism, pervasive developmental disorders, and related disabilities the development of appropriate community services, including education, residences, jobs/job training programs, and of individually appropriate and adequate support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communicative and social needs; of adequate supports to every family to assist them in maintaining their disabled family member in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individual's behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.

MEMBERSHIP FORM

Because I endorse the principles of the Autism National Committee, I would like to (circle one):

JOIN NOW

RENEW MY MEMBERSHIP

NAME _____

ADDRESS _____

CITY, STATE, ZIP _____

PHONE _____

E-MAIL _____

I AM A (circle): Family member Person with autism Friend Professional (field _____)

Annual membership: \$30.00. Persons with autism: \$10.00. Supporting membership: \$75.00

I am enclosing an extra \$ _____ to speed up the good work.

Make checks payable to Autism National Committee and mail to:

Autism National Committee

Wade Hitzing, Treasurer

1045 Wittman Drive

Fort Myers, FL, 33919

The Autism National Committee is a 501 (c) (3) charitable organization. Your contributions are tax deductible and will be promptly acknowledged for your records

**The Autism National Committee
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Time to Renew or Join Today!

**Annual membership begins in January
(Membership form on page 7)**



THE COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c)(3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to Gail Gillingham at PO Box 11245, Main Post Office, Edmonton, Alberta, T5J 3K5, Canada, or e-mail her at: exgr@telus.net.

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