



Dedicated to "Medically Necessary" autism treatment

# The Inaugural FEAT BC newsletter

Welcome to the inaugural FEAT of B.C. Newsletter! In the short time that FEAT of B.C. has been working for our kids, we've accomplished much. To help our membership stay connected, we have established this newsletter. Through the motivation and hard work of Judy Anderson and Arleene Ewing, the FEAT BC newsletter was conceived and launched. We all want to convey our appreciation to them for helping bind our organization closer together. We are certain it will become a valuable source of news and information about behavioural autism treatment in B.C.

## Who We Are

Families for Early Autism Treatment of British Columbia (F.E.A.T. of B.C.) is dedicated to bring the most effective type of autism treatment available, to the children of British Columbia Applied (Lovaas-type Behavior Analysis - A.B.A.). A central part of our mission is to make Lovaas-type A.B.A. autism treatment universally accessible to all B.C. children afflicted with autism spectrum disorders regardless of ability to pay.

#### F.E.A.T. of B.C.:

• is a clearing house for information on Lovaas-style autism treatment

• is an entry point to behavioural treatment for newly diagnosed children to connect with treatment professionals and help set up programs

• is a society that offers education via workshops and seminars with recognized leaders in the field of Lovaastype A.B.A.

• educates psychiatrists, pediatricians and educational professionals regarding the effectiveness and importance of early autism diagnosis and intensive treatment via Lovaastype A.B.A.

• has obtained the formal endorsement of 63 B.C. psychiatrists certifying Lovaas-type A.B.A. as medically necessary treatment that must be made universally available and funded by the Medical Services Plan of British Columbia or the Ministry of Health or both. 2

## **Autism Education Society**



FEAT BC established a separate. nonprofit, charitable organization in 1997 called A.E.S., the Autism Education Society. The goal of A.E.S. is to esatblish an academic "Chair" at the University of British Columbia to teach Lovaas-style behavioural treatment and thereby develop a source of "home grown" BC professionals (Therapists and Behavioral Consultants). The target is one million dollars to fund the new program. In the summer of 1997, A.E.S. cosponsored the 1st Annual Monarch Invitational Celebrity Golf Tournament in support of A.E.S. Proceeds from the tournament have enabled A.E.S. to set up the first course at U.B.C. taught by an expert in Lovaas-type A.B.A., Dr. Tristan Smith -Summer 1998, U.B.C.

Please call Sarina Kier (604)264-8487 with your funding raising ideas for A.E.S.

# **Informing Politicians**

FEAT BC has prepared an information brief for Politicians. FEAT BC members have been requested to meet with their M.P. or M.L.A. to present the brief and (if they are parents of an autistic child) outline their individual situation. A package will be available at the FEAT BC Discussion Group meetings (or call FEAT BC at 604-534-6956 or 604-925-4401.

## F.E.A.T. of BC. and the Media

In November 1997, BCTV news aired a significant story about a family - the Engers - forced to leave B.C. for Health Care because they cannot afford the cost of A.B.A. treatment. The B.C. government does not cover the cost of medically necesary autism treatment, and with no private sources of funding, the engers and their son were forced to leave their home for Alberta. The story of the Engers was also covered in the Vancouver Sun by the medical journalist.

If members of FEAT have the opportunity to give interviews to the media, please ask for the FEAT BC autism media briefs and video materials. Have the journalist contact F.E.A.T. of B.C. for more information.

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The FEAT BC Newsletter is published by Families for Early Autism Treatment of BC 20641 - 46 Ave., Langley BC V3A 3H8 Ph. 604-534-6956 Fx. 604-534-9527	Managing Editors: Judy Anderson & Arleene Ewing Contributors: Judy Anderson & Sabrina Freeman Design & Layout: Isaac Tamir
email: FEATbc@biogate.com web-site: http://fox.nstn.ca/~zacktam/FEATbc/	F.E.A.T. of B.C. is a non-profit organization of parents and concerned professionals. FEAT BC is a 100% volunteer organization there are no paid staff members We do not
Comments or suggestions? Please contact: Judy Anderson (604)986-1975 or Arleene Ewing (604)984-7232	recieve any government financial support for work we do on behalf of children with autism and their families.

# The FEAT BC Petition

FEAT BC has launched a petition drive directed towards the Premier of B.C., Glen Clark. The petition reads as follows:

"We the undersigned, agree that the right to medicare, as one of the defining features of Canadian Nationhood, must include medically necessary autism treatment for all children who require it. It is fundamental that a child's access to medically necessary autism treatment be solely based on need and not individual ability to pay. We agree with sixty-three (63) B.C. Psychiatrists who believe medically necessary autism treatment must by fully funded by the Medical Services Plan, the B.C. Ministry of Health or both. We support the immediate establishment of an independent task force to find a way to provide medically necessary health care for all children with autism."

Members of FEAT who would like copies of this petition to gain support for the cause of universally accessible, publicly funded Lovaas Autism Treatment, please contact F.E.A.T. of B.C. Many thanks to Diana Thomas for all her hard work and vision establishing this petition drive. FEAT BC Parent Group Meetings

The FEAT BC Parent group meets on the third Wednesday of each month.

- Time: 7:00 pm
- Place: St. Francis in the Wood, 4773 South Piccadilly, West Vancouver

Phone Jean Lewis at (604)925-4401 for more information. A map is available for you to download at:

http://digital-web/FEATbc/Map or ask us for a copy by fax or mail. At the last meeting on November 1997, these were topics discussed:

#### FEAT BC History, Objectives & Initiatives

- · the Checklist for Autism in Toddlers
- upcoming F.E.A.T. workshops
- brief to Members of Parliament
- Autism Education Society

#### **Future Topics for Discussion**

- sharing information on consultants
- how to educate the educators
- school integration
- sharing of programming ideas, materials, and teaching aids
- siblings
- · parent referral, and
- formalized data collection

A copy of the Minutes will be available at the January 21st meeting or from Judy Anderson at (604)986-1975.

#### Next FEAT BC Discussion Group Meeting: January 21, 1998

Topic: How to find, critique and maintain experienced therapists.

#### Upcoming FEAT BC Discussion Group Meeting: February 18, 1998

Topic: How to secure public funding for your autism treatment program.

Another Happy FEAT Kid!

When a professional asks you how you have done the impossible, tell them, "it's simple, I'm the Parent."



## What's Happening

*These are upcoming events that have A.B.A. content.* 

# • FEAT BC Early Intervention Workshop

This two-day workshop is a must! Shelley Davis, M.A. J.D., a well known Lovaas-style behavioral consultant will provide an in-depth introduction to the fundamentals of behavioural treatment of young children with autism. The workshop will include theoretical background as well as many aspects of the practical implementation for the behavioural treatment method.

where: U.B.C.

when: March 28 & 29, 1998

cost: \$25.00 for the weekend plus \$5.00 per day for parking

For more information contact: FEAT BC (604)534-6956.

#### • Science in Autism Treatment

This conference includes a large number of the "players" in the A.B.A. world. Speakers include John McEachin, Ph.D., Tristam Smith, Ph.D., Gina Green, Ph.D., James Mulick, Ph.D. (a fellow parent), Patricia Krantz, Ph.D., Ray Romanczuk, Ph.D. and Catherine Maurice, Ph.D. (also a parent). where: Pittsburgh, Pennsylvania when: March 20 & 21, 1998 For more information, please go to their web site:

http://www.pitt.edu/~mrkool

#### • FEAT BC Autism Behavioral Therapists Training Workshop

Bring you therapy team up to speed with a high powered one-day workshop delivered by two capable and experienced senior therapists. This workshop, given by **Sharon Baxter** & **Rachel Russell** focuses on the practical aspects of delivering effective behavioural autism treatment.

where: U.B.C.

when: April, 1998 (date to be decided) 9 a.m. to 5 p.m.

cost: \$15.00 for the workshop plus \$5.00 for parking

For more information contact: Sharon Baxter (604)531-2467

#### • F.E.A.T. of Washington

Our FEAT neighbours are sponsoring a twoday conference featuring a number of prominent people in the field. Speakers: **Catherine Maurice, Ph.D., Gina Green,** 

Catherine Maurice, Ph.D., Gina Green, Ph.D., Tristan Smith, Ph.D., Eric London, MD., Geraldine Dawson, Ph.D., et. al. where: Meydenbauer Centre, Bellevue, Washington when: May 2-3, 1998 For more information: (206)499-FEAT or

http://members/aol.com/featwa or email FEATWA@aol.com

#### • ACT NOW Conference

Although the ACT NOW conference is not sponsored by folks with an ABA focus, there are notable ABA speakers such as Richard Foxx, Ph.D. and Laura Schreibman, Ph.D. In addition, a renowned scientist, Isabelle Rapin, Ph.D. - Albert Einstein College of Medicine in New York - will be speaking in Kamloops. She will be fascinating for anyone interested in the neurobiology of autism and the search for a cure.

Where: Kamloops, B.C.

When: April 23, 24, and 25, 1998 Cost: \$

Dr. Jill Calder, XXXXX, is a member of FEAT BC and we thank her for including the ABA perspective in the Kamloops conference.

For more information call: Ph. (250)851-4033 fax (250)376-2231

## ABA on the Net

• F.E.A.T. of B.C. http://fox.nstn.ca/~zacktam/FEATbc

• The F.E.A.T. of B.C. Discussion Group http://chat.digital-web.net/

To request a user account, send an email to FEAT of BC at: FEATbc@biogate.com

• The Recovery Zone http://pages.prodigy.com/dporcari/ recovery\_zone.html/

• The "ME List" rallen@INDYVAX.IUPUI.EDU

A mailing list of over 1300, discussing topics related to A.B.A. program. Send a note to Ruth telling her why you would like to sign up and request it in digest form - this is a VERY active list.

• FEAT of Washington

• FEAT of Sacramento

· FEAT of Oregon

• FEAT of Nebraska

## **Contribution Authors**

The FEAT BC newsletter needs contributing writers. Any FEAT BC parents who want to contribute, we welcome your input. FEAT BC members who:

- · have a journalism background
- have a science background

• want to be part of this in any capacity. Please join this part of our important movement.

## **Food for Thought**

#### "A.B.A. Angels"

I remember three years ago when we began setting up the A.B.A. program for our son, I told my husband that Rvan's autism would expose us to some really special people, people unlike ourselves (we are both business people) who have chosen to work with special needs children and to help these kids become the best they can be. Well, today I know how true those words are. During the last three years, we have gone through the exhausting and heart wrenching process of hiring fifteen A.B.A. therapists. two Teaching Aids. I am not a religious person, but I believe that we have been blessed with Angels who chose to work with our son. They have hearts of gold (in order to love our son as we do), infinite patience (in order to teach his autistic brain to learn) and wills of steel (in order to keep our little monkey on task). And the wonderful thing is Ryan performs for his Angels and as a result he will reach his maximum potential.

Judy Anderson

# The "Checklist for Autism in Toddlers" (The CHAT)

F.E.A.T. of .B.C recently completed the CHAT project, an effort to improve early autism diagnostic capability of B.C.'s primary care physicians and pediatricians. FEAT BC sent the CHAT to 3900 General Practitioners and Pediatricians in the province. This is already making a tremendous difference. Children are being diagnosed earlier and referred to us for more information on intensive Lovaas-style autism treatment.

The CHAT, Checklist for Autism in Toddlers, is a highly effective diagnostic tool, originally developed in Britain by Dr. Simon Baron-Cohen. Most physicians have now incorporated the CHAT into their practice since it is the most accurate, elegant means of early autism diagnosis that can be implemented in a short, 10 minute, office-based evaluation.

CHAT The Checklist for Artism in Toddlers A Screening Tool	CHAT The Checklist for Auton in Tuddlers A Saccuing Tool
Child's Name	SECTION B: GP or EV Observation i. During the appointment, has the child made eye contact with you?
Date of Birth Age	*ii. Get child's attention, then point across the room at an interesting object and say, "Oh, look! There's a (name of toy)!" Watch the child's fees. Does the child look across to see what you are pointing at?"
To be used by GP's or Health Visitors during the 18 month developmental check-up.	*iii. Get the child's attention, then give child a miniature toy cup and teapot and say, "Can you make a cup of tea?" Does the child pretend to pour out tea, drink it, etc." <sup>3</sup>
SECTION A: Ask Parent 1. Does your child enjoy being swung, bounced on your knee, etc.?	<ul> <li>*iv. Say to the child, "Where's the light?", or "Show me the light?"</li> <li>Does the child point with his/her index finger at the light?<sup>2</sup></li> </ul>
<ol> <li>Doesyour child take an interest in other children?</li> <li>Doesyour child like climbing on frings, such as up stairs?</li> </ol>	<ul> <li>v. Can the child build a tower of blacks? (If so, how many?) (Number of blocks)</li> </ul>
S. Does your child enjoy playing peak-a-toachide-and-asok?     4. Does your child ever proteind, for example, to make a cop of tea     using a vay cup and keapot, or pretend other: things (pouring juice)?	<ul> <li>Indicates critical questions that are most indicative of autistic characteristics.</li> </ul>
6. Does your child ever use his/her index finger to point, to ask for     something?	<sup>1</sup> (To record yes on this item, ensure the child hasnot simply looked at your hand, but has actually looked at the object you are pointing at.)
*7. Does your child ever use his/her index finger to point, to indicate interest in something?	<sup>2</sup> (Ff yea can elicit an example of pectending in sume other game, score a yes on this item.)
<ol> <li>Can your child play properly with small toys (e.g.: cars or blocks) without just mouthing, fiddling, or dropping them?</li> </ol>	<sup>3</sup> (Repeat this with, "Where's the Teddy?" or some other unreachable object; if child does not understand the word "light." To record a yes on this item, the child must have looked up at your face around the time of pointing.)
9. Does your child ever bring objects over to you (parent), to show you scratching?	The British Journal of Psychiatry (1996), 168, pp. 158-163. The British Journal of Psychiatry (1992), 161, pp. 839-843.

## The FEAT BC Classifieds

#### Consultants

Anyone involved with **Autism Partnership** please contact Arleene Ewing (604)984-7232 to discuss how your program is going. Arleene will prepare a brief of (anonymous if so desired) comments with copies available to anyone interested. If you attended the November 12/ 97 Autism Partnership workshop with Sandy Slater, Arleene would very much like your comments regarding the workshop.

#### **Therapist Required**

We are looking for a male therapist to work with a very bright 6 year old. If interested, please contact: Sarina Kier (604)264-8487

#### **Help Wanted**

Early Intervention Workshop with Shelley Davis March 28 & 29, 1998 at U.B.C. Volunteers needed for registration, refreshments, to pursue donations or coordination. Please contact Jean Lewis (604)925-4401.

#### **Discussion/Support Group**

f you would like to be paired up with another A.B.A. family in your area with similar age child please contact Jean Lewis (604)925-4401.

Please use this section to advertise for things that are needed or things that are available for sale (or free), for example: specific A.B.A. therapy materials, therapists, baby-sitters, etc.

### **NEW: FEAT BC Internet Discussion Group**

When you are between *FEAT BC* Discussion Group Meetings, but still want to talk...

...you can meet and chat with other FEAT members at the *FEAT BC* Discussion group on the internet - for free.

Simply use your web browser to visit http://chat.digital-web.net and you're there. No matter where you live, you can always chat with other FEAT BC members at the Discussion group web site. It's also a great way to keep up with what's going on in BC. All messages other *FEAT BC* members post to the group can be sent automatically to your email box.



#### How Does it Work?

When you go to the **FEAT BC** Discussion web site, click on a topic area you want to talk about, then type a message and click on a button to "post" your message. As soon as you post a message. it's available for everyone else to read and respond to from their computer -- it's like being at a regular discussion group... except no one needs to leave home. Other FEAT BC members can instantly read your message and respond to your thoughts with a message of their own. Only FEAT BC members are allowed to post messages with a user ID so the discussions will be meaningful. If they prefer, members have the op tion to post anonymously.

If you want to try this new way to chat, go to the web site right now to try a test message. The testing area is open to everyone (no User ID needed). Then, if you want to post messages to the other topic areas, give us a call or send us a email and we will set you up in 24 to 48 hours -- it's easy, fast and it will help FEAT BC members stay in touch and help share information, ideas or maybe a poem. Please give us a call or send us a note.

FEAT of BC Ph. 604-534-6956 Fx. 604-534-9527 email: FEATbc@biogate.com

F.E.A.T. of B.C., 20641 46th Ave., Langley, B.C. V3A 3H8

