

SHARE & CARE

THE RECOVERY OF HOPE ~ THE HOPE OF RECOVERY

SEEKING CAREGIVERS WITH EXPERIENCE

Is that you?

A groundbreaking research study needs your help to succeed

Very soon AMI families like yours will be receiving a letter in the mail. It will ask the principal caregiver in your family to participate in a study investigating the impact of caring for a relative with mental illness. There's a postage-paid response card with the letter, which you mail back **only** if you decide not to participate.

Executive director Ella Amir hopes no cards get returned.

The project is her baby, a key part of the work she's doing towards her PhD degree at Concordia. To her knowledge, there's never been a study exactly like it.

"My interest stems from working with

families at AMI for the past 18 years," Amir says. "After all that time there are still many questions I can't answer. For instance, why are caregivers' experiences in looking after their ill relatives so varied? My goal is to track down the contributing factors that make everyone's situation unique."

Time well spent

Your participation entails completing a questionnaire. Two, actually. The first



An exciting opportunity for both Amir and Wrosch. 2005 winner of the Institute of Aging's Special Recognition Prize for New Investigators in Research on Aging, Wrosch was honored in the New York Times Magazine's "7th Annual Year in Ideas," where his proposition that quitting may be good for you was called "one of the world's 70 most intriguing discoveries in 2007"

you'll receive this spring; a follow-up will be sent in a year or so to learn if anything in your situation has changed. Amir asks

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IT'S A GO

You can set up and start contributing to a Registered Disability Savings Plan right now

The royal assent received last December means the Disability Savings Plan (DSP), proposed two federal budgets ago, now has official legal status.

Designed to help secure a more comfortable future for people with disabilities, the DSP is modeled on the RSP idea, but with important differences.

The DSP Plan

- Contributions permitted by the individual, family members or

friends. This includes those qualifying for the disability tax credit, their parent or legal representative.

- No annual limit on contributions, but a lifetime limit of \$200,000.
- Interest earned inside the plan grows tax-deferred.
- No restrictions on when or how the funds can be used.

The DSP Grant will match contributions for 20 years. Maximum life-

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Ottawa has promised \$110 million to the Mental Health Commission of Canada for research to help the homeless living with mental illness. The Commission will use the funding to set up demonstration research projects in Moncton, Montreal, Toronto, Winnipeg and Vancouver. Click on:

www.mentalhealthcommission.ca

Caregivers ... continued from page 1

that you complete and return the first questionnaire within a month. That will be easy enough. Some questions require just a checkmark in the appropriate box, others are open-ended, allowing you to add extra information if you choose. Amir calculates the work should take you about an hour, not more than an hour and a half.

Caregiving techniques and strategies can be taught, learned and practiced.

Rest assured that the details you supply are confidential. The information compiled will be used strictly for research purposes. What's being studied are circumstances rather than individuals, different approaches to managing specific challenges and patterns of behavior that might ultimately contribute to better physical and mental health for caregivers.

A good match

Amir became an official PhD candidate last September. She chose as her supervisor Dr. Carsten Wrosch, an associate professor in Concordia's psychology department since 2001. Wrosch is no stranger to the subject of caregiving. To learn how people manage stressful encounters in order to stay happy and healthy, he has done projects with caregivers of the elderly and with parents of sick children. Caring for the elderly and for Alzheimer's patients are frequent research topics, and although Wrosch suspects that many circumstances will be similar, he's not aware of any other studies done exclusively on caregiving and mental illness. So not only is Amir's project a welcome challenge, he thinks it may well be the first of its kind. And it's very much needed.

"Everything I've learned points to caregiving as a risk factor," Wrosch says. "Caregivers are usually more depressed than non-caregivers. They show signs of

physical difficulties. They can even die earlier. And yet, what's intriguing is that it doesn't happen to everyone. Some people become depressed and sick, while with others it's just the opposite. Why is that? Do they think differently? How are their lives different?"

If Amir's research can identify those factors and behaviors that distinguish caregivers who cope in a positive way, it will have what Wrosch calls "high applied value." Caregiving techniques and strategies can be taught, learned and practiced. In other words, people can be trained to become successful managers of their stressful situations. But before that can happen, the key factors have to be identified. And that's what makes Amir's project so vital, so important — not only for AMI families, but for anyone caring for a relative ill with a brain disorder.

Getting the word out

The traditional goal for researchers is publication in scientific journals, so oth-

ers in the field can learn and integrate the findings into their work. But Wrosch is thinking outside the box. Why not hold a seminar to discuss the conclusions with the caregivers who participated?

Amir likes that idea and goes further. She sees her work as conferring a practical benefit on all AMI members and hopes it will eventually translate into more effective approaches to AMI's education courses and seminars, better understanding and happier lives for every family member living with a mental illness situation.

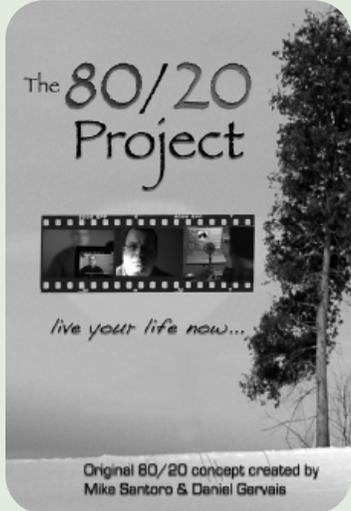
But first things first. The job right now is mailing the first questionnaire out — and getting the completed forms back. Yes, your participation is encouraged and hoped-for, but don't feel you're being pressured. There won't be consequences if you choose not to sign on. Your decision won't affect your AMI membership or cool your welcome in the organization in any way.

For Amir this is much more than an opportunity to launch a scientific inquiry, or to be published, or even to acquire a coveted degree. "The PhD would be the icing on the cake," she says. "What really motivates me is I see this as a way to contribute something significant, something beyond what I've been able to do up till now at AMI. Who knows, one day it may even be considered my legacy." □

MIKE'S RECOVERY STORY ON DVD

Mike Santoro is enjoying a very happy life, thank you, despite his severe mental illness. His 80/20 Project DVD, officially launched last January, is now for sale on Santoro's website.

80 and 20 are percentages. The 80 stands for Santoro's efforts in dealing with his illness. The 20 refers to medication. The DVD concentrates on the 80 percent and it's 100 percent worth having. Go to www.MikesStory.com



OUR EDUCATION & OUTREACH PROGRAM IS GOING WHERE IT'S NEVER GONE BEFORE

Nine years ago we launched a program to speak to high school students about mental illness. We're still doing that — and a lot more besides. You could say the program has come of age.

“Our high school list is growing,” says program coordinator Lori Goodhand. “But over the past year and a half we've added a good number of CEGEPs and universities as well. We're also meeting with community groups who work with consumers and want to learn more.”



Finucan and Goodhand: presentations that work on two levels

“They have a program where community groups visit for guided tours,” explains Goodhand. “Sometimes that includes psychiatric patients from the General and the Allan. The museum wanted to be sure their guides could relate to them in a helpful way.”

50 and counting

Over 50 schools and community organizations are on our education roster this year. They receive presentations that are engrossing and effective. First come the hard facts, the science of brain disorders. Then comes the humanity. The program has a pool of speakers, consumers who happily share stories of their experiences. They're now getting paid for their time and effort. “Personalizing mental illness is one of the best tools for reducing stigma,” says Goodhand. “Our presenters are crucial to our success. They deliver a message of hope, that if you develop a mental illness your life's not over. Recognize it, deal with it and work towards your recovery, and you can live very well.”

Someone who's doing just that is presenter Jason Finucan. The 31-year old works in Development & Alumnae Relations at McGill, where he manages a portion of the university's \$9 million annual fund. The story of his illness and recovery are inspirational, best told as we heard it, in his own words.

Jason Finucan: Three years ago I was a healthy, happy, energetic young man of 28 with a career at McGill and engaged to be married. I suddenly got depressed and didn't know why. Soon I began a cycle of depression and hypomania. It was debilitating at first, then it got worse. I couldn't work, in fact I could barely function. Ultimately I was hospitalized. I'd had a manic episode that lasted five days, four of which I didn't sleep.

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SPRING 2008

GUEST SPEAKER EVENINGS

Mondays 7:30pm 4333 Côte Ste-Catherine Road

May 26: Sylvie Albert, Sylvia Smith, Our Harbour representative. *Reclaiming your life after a mental illness*

EDUCATION

7:00-9:00pm at AMI

Mood and Thought Disorders

6-session program begins April 24

Roundtable Discussions

Sexuality and Mental Illness. Drs. Irving Binik and Gerry Wiviott, McGill University
April 30

SUPPORT GROUPS

Mondays 7:30pm 4333 Côte Ste-Catherine Road unless otherwise indicated

FAMILY for relatives

April 7, 14, 28; May 5, 12; June 2, 16, 23

SOUTH SHORE for relatives

Wednesdays 6:30pm
Call 514-486-1448 for location
April 2, 16, 30; May 14, 28; June 11, 25

PARENTS of adult children

7:00pm at AMI
April 17; May 13; June 17

SIBLINGS AND ADULT CHILDREN

April 14; May 12; June 23

BIPOLAR DISORDER

for consumers and relatives
April 7; May 5; June 2

DEPRESSION for consumers and relatives

April 28; May 12; June 16

OBSESSIVE COMPULSIVE DISORDER for consumers and relatives

April 28; May 12; June 16

KALEIDOSCOPE for consumers

April 14; May 5; June 23

LIFELINE for consumers

Thursdays 1:00-3:00pm
Alternative Centregens, 5770 Auteuil, Brossard
For more information, call 450-445-5427

ANNUAL GENERAL MEETING

June 9 (details to come)

BOARD MEETINGS

Tuesdays 7:00pm at AMI
April 1; May 6; June 3

Celebrating Beppie and Pieter

A HEARTFELT SALUTE TO TWO FOUNDING MEMBERS FROM AMI'S SOUTH SHORE SUPPORT GROUP

During their holiday celebration last December, members of our South Shore support group raised a toast in thank-you to Beppie and Pieter Boudens for their unflinching commitment over the years. Here, RUTH ROACH's tribute (edited for space).

For over 25 years, Pieter and Beppie have been synonymous with AMI-Québec. Together with Doug and Elsie Richardson and another couple, they started our South Shore support group about 15 years ago. Pieter has spent over 10 years representing us on the board of directors and at FFAPPAM, chairing sub-committees, going to meetings and conferences, giving so much of his time and energy.

Pieter's ability to capture an audience is dynamic, whether one-on-one, a small group or in a crowded lecture hall. He does it with humor, pathos and poetry. This gentle man with the quiet voice tinged with a soft Dutch accent keeps his distance from the fray. But his enigmatic smile, his cool, calm and collected demeanor belie the anger towards injustice, the determination to fight stigma and the dedication to stand up and speak for families affected by mental illness.

Beppie is the heart and soul of our

South Shore support group, its quintessential mother. She gathers us together, keeps us in order and knows the joys and heartaches of each and every one of us. She listens without judgment, searches for information and gives comfort and encouragement. Her phone line is open till midnight every day of the year.

Her artistic talents are known to us all.

Each year at Christmas she hands us a white candle delicately decorated or sends one of

her beautifully crafted pressed-flower cards to any of us who might be sick, hospitalized or in grief. She never forgets the anniversary of those who have lost a child.

Believe it or not, Pieter and Beppie do have a life beyond AMI-Québec. Both are actively involved in their Dutch community. They spend summers working in their

garden or at their country home. They travel to Holland or Toronto to see their families. Beppie makes her yearly pilgrimage to Vancouver to remember [son] Gus. They both love music and poetry, nature and art. We are honored to be among the many whose lives they have touched and we thank them for



Beppie and Pieter Boudens: honored by their presence

the time and energy they have devoted to the South Shore support group. □

Scientists provide NARSAD's website with a goldmine of research news about mental illnesses

It describes itself as the world's leading charity dedicated to mental health research. A private, not-for-profit charity based in Long Island, NY, NARSAD funds scientists working on major projects to uncover causes, develop new treatments and eventually even conquer a variety of mental illnesses.

The website, while U.S.-oriented, offers an abundance of news from the scientific front. Here, information from a few of the recent studies led by NARSAD researchers.

Soaring rates of bipolar diagnosis among U.S. youth

An analysis of national data reveals that the number of Americans ages 19 and younger diagnosed with bipolar disorder is currently 40 times greater than it was a decade ago. This figure

compares with a twofold increase in bipolar diagnosis in the adult population.

Researchers estimate that from 1994-1995 the number of office visits resulting in a diagnosis of bipolar disorder for youths was 25 out of every 100,000 people. By 2002-2003, that number had jumped to 1,002 per 100,000 visits.

While the cause of the increase is unclear, some interpret the data as revealing more about trends in diagnosis than actual incidence of the illness and claim it reflects what has been called either "a recent tendency to over-diagnose bipolar disorder in young people, a correction of historical under-recognition or a combination of both."

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PREVENTING RELAPSE

No one is more important than consumers themselves

The last issue of *Share&Care* reported on a stages-of-relapse model developed by U.S. psychologist Christopher S. Amenson. Dr. Amenson describes the five-stage cycle of recurrent mental illness: stability, early warnings of relapse, all-out relapse, symptom remission and back to recovery. He suggests ways families can reduce the relapse risk, minimize its impact should it happen and hasten their relative's journey back to a life in balance.

The second half of Amenson's model is this relapse-prevention plan developed specifically for consumers. Which is not to say families shouldn't be involved. It is suggested that, depending on individual circumstances, families can even help develop and implement the plan. Most important, everyone needs to be able to identify the warning signs of an impending relapse.

Relapse Prevention Plan

1. Maintain wellness

- Get sufficient sleep
- Develop good eating habits
- Find time for exercise, relaxation and meaningful activities
- Work to build satisfying relationships
- Avoid symptom triggers

2. Take charge

- Learn about mental illness
- Become involved in your treatment
- Join a consumer or advocacy group

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TRIBUTES & MEMORIALS

In honor of Anne Sutton Brown
Lorna Moscovitch

In honor of Evelyn Ortenberg
Elsie Shriar

In honor of Georgina and Gordon Peacock
Judy Phillipson

In honor of Sandy Voronka
Judy Phillipson

In honor of Anne O'Neil
Judy Phillipson

In honor of Bernadette Laroche
Judy Phillipson

In honor of Glenys Vaughan
Judy Phillipson

In honor of Shirley Steele
Judy Phillipson

In honor of Dr. & Mrs. José Jimenez
Judy Phillipson

In honor of Moira Bettinville
Judy Phillipson

In honor of Marianne Brown
Judy Phillipson

In honor of Marc Amzallag
Alain Amzallag

In honor of Gisèle Amzallag
Alain Amzallag

In honor of Hannah Lévy
Alain Amzallag

In honor of Myriam Moryoussef
Alain Amzallag

In honor of Judy Phillipson
Bernadette Laroche

In honor of Elizabeth and Jim Tremain
Frances Sault

In honor of Lorna Moscovitch
Miriam and Cecil Charron

In honor of Lorne Rubin
Bernard Rosen

In honor of Steve Belitzky
Sherry Ellen

In honor of Katja Kessin
Terry Trainor

In honor of Ena Steer
Nancy Cree

In memory of Sylvia Hammer
Ella Macklin

In memory of Joan Friedman
Elaine Podbere

In memory of Max Silver
Shirley and Bob Smith
Marylin Block
Kay Simpson
Joanne Smith
Claudia and Jerry Ikeman
Lorna and David Moscovitch

In memory of Sara Mintzberg
Pat and Paul Rubin

In memory of Harry Baker
Pat and Paul Rubin

In memory of Gertrude Rosenberg
Silver and Louis Silver
Debby Mayman and family

In memory of Hester Katz
Margaret Golick

In memory of Lynda Percival
John Done

In memory of Natalia Toyota
Jack Toyota

In memory of Sarah Gaulin
Rita Chazin

In memory of Sonia Marcu
Mary Ruth and Ronald Gehr
Gloria Aronoff

In memory of Ada Louisa Jones née Putman
Marta and John Jones

In memory of Joan, Watson and Stuart Gall
John Gall

In memory of Seymour Miller
Sylvia and Bill Klein

In memory of Nora Zunenshine
Pat and Paul Rubin

In memory of Gordon Calderhead
Kay Simpson

In memory of May Gruman
Kay Simpson

In memory of Elsie Johns
Kay Simpson

In memory of Georgia M. Dawe
Arthur G. Dawe

In memory of Monty Berger
Kay Simpson

In memory of Vera Wood
Kay Simpson

In memory of Barbara Swan
Kay Simpson

In memory of Mark Ruckenstein
Jean Berger

AMI-Québec extends sympathy to the bereaved and appreciation to all donors for their generosity. For information, please phone 514-486-1448.

Education & Outreach ... continued from page 3

Share&Care: You never had a hint before then that anything was wrong?

JF: Now I realize the bipolar had begun simmering when I was 26. But I was stunned that a healthy life could come to a screeching halt in such a dramatic way. I was off work for a year. It destroyed my relationship with my fiancée. By a stroke of luck, I joined AMI so I could take the Mood & Thought Disorders course. That's when I heard Mike Santoro [administrative assistant] speak. He talked about being sick, recovering and living well. It was a revelation, the first time in a year and a half that I'd heard such a message. I thought, "Here's a really great goal. I'd like to get well so I could do what Mike's doing." So along with taking the course, I researched everything I could on bipolar and read up about medicines. I focused on getting well and staying well.

After about two years of persistence and self-education, I could say I owned my illness. I understood it. I wasn't only at the whim of it. It was about this same time that, finally, I was correctly diagnosed and put on the right medication, lithium. Once I felt sure I had navigated my way back to health, I called AMI and told them I was ready to help. It was the first time I had volunteered for anything outside of my work.

S&C: What are you doing now to maintain your recovery?

JF: It was very bleak and frightening to be sick. You get trapped into not seeing beyond that situation. I haven't had a depression or hypomania episode since I changed my attitude and was put on the right medication dosage. Now I try to treat my personal life as carefully as I treat my loved ones and my work. I make sure I enjoy my work, but I don't overdo it. I'm careful how I eat and sleep. With the life-management skills I've learned I'm living really well.

Promote understanding, stamp out stigma and earn some cash, too

As a consumer, you can do what no one else can to enlighten the public to the truth of surviving and living with a mental illness.

Our Education & Outreach program needs your voice as a presenter. We'll give you the training and any other help you need, and we'll pay you an honorarium per speaking occasion.

Your contribution is vital to the continuing success of this important program. Phone or send a note or email to Lori Goodhand at the office. 514-486-1448; education@amiquebec.org

S&C: Is that your message when you present?

JF: I tell my story. I try to make it clear that stigma, fear, misunderstanding and a lack of communication are barriers to getting the upper hand in dealing with mental illness. Those barriers hurt everyone, consumers, their friends and their families, and they exist only out of ignorance.

S&C: Some people are still clinging to the idea that recovery is impossible. What do you say to them?

JF: That's a defeatist attitude. Those of us in recovery are persistent and determined not to give in. With the right medication I believe you can recover from the acute expression of your illness, the symptoms. But even more important, you have to work on the way you live the rest of your life. If those things are in place, anyone can do what I did. □

Relapse ... continued from page 5

3. Manage your medication

- Take as prescribed
- Understand its role in your treatment and possible side effects
- Communicate with your physician

4. Develop coping skills

- Avoid stressful people and situations
- Work on managing stress, solving problems and communicating effectively
- Express needs assertively

5. Expand your support network

- Your circle might include family, friends, other consumers and healthcare providers

6. Recognize warning signs

- Return of former symptoms
- Increase in daily symptoms
- Changes in feelings, behavior or biological rhythms
- Notice the concern of others

7. Keep a daily record

- Chart symptoms and rate warning signs: 1=absent, 2=slight, 3=moderate, 4=severe
- Note changes in warning signs
- Note returning and worsening symptoms

8. Develop a personal action plan

- List names and phone numbers
- Write directions to hospital
- Identify a support person
- Decide whom to contact and when
- Distribute plan to concerned parties

9. Conduct a relapse drill

- Review steps 1–8
- Discuss possible responses
- Choose strategies
- Assign roles and responsibilities
- Plan for future implementation

10. Respond to warning signs

- Pull back for a while
- Choose calming activities
- Reach out to others
- Temporarily adjust expectations
- Maintain daily routine

11. Cultivate a personal garden

- Nourish your talents
- Explore your interests
- Seek out new people and opportunities
- Make fulfilling lifestyle changes

Information taken from *Promoting Recovery and Preventing Relapse* by Diane T. Marsh in *A Family-Focused Approach to Serious Mental Illness*, Practitioner's Resource Series, 2001.

WHY DEPRESSION STARTS

A new study led by Queen's University scientist DR. KATE HARKNESS is investigating the factors that trigger the first occurrence of the illness in young adults

The transition from adolescence to adulthood is a time of great stress as young people take on the pressures and heightened responsibilities of independent living, professional employment and adult relationships. While most negotiate this transition successfully, many do not. Young adulthood is the period of greatest risk for the onset of serious mental illness, including major depression. According to recent reports, one in seven people ages 18-25 has experienced a first attack of depression. An alarming 50-60 percent of these will go on to suffer multiple recurrent episodes throughout their adult lives. These individuals fail to reach their potential as adults because of the devastation wrought by the illness.

The study being done by Harkness and scientists at the Centre for Addiction and Mental Health [in Toronto] seeks to reverse this pattern by examining the factors that cause the initial appearance of depression in young adulthood. It's the first study to focus specifically on the first episode of the illness in order to uncover its underlying causes. Understanding what causes the disorder will facilitate the early identification and treatment of

young people at risk and greatly help clinicians to reduce the chances of recurrence.

Important risk factors

Depression runs in families. A big reason for this is that particular genes are passed down from parent to child. New research suggests that the impact of genes on depression is not direct, but instead acts through the environment. Those with a specific genetic marker in the serotonin system are much more likely to get depressed in the face of stress in their environment than are people without this marker. The genetic variant heightens sensitivity to stress so that individuals affected break down when faced with stressors of relatively less impact.

Many forms of stress can precipitate an episode of depression, from severe emotional or sexual abuse in childhood to the loss of a job or the breakup of a romantic relationship in adulthood. Not everyone who experiences these events becomes depressed, however. Why are some people resilient in the face of stress while others experience debilitating depression? Again, the answer lies in the important interaction between genes and the envi-

ronment. Individuals with an at-risk genetic profile are more likely to get depressed because of stress. They also require less severe levels of stress to get depressed than individuals without their same genetic profile.

Testing the variant

Dr. Harkness and her colleagues believe that this model can help explain why young people get depressed the very first time. Specifically they're testing the prediction that young adults with a particular variant of the serotonin transporter gene will require less severe levels of stress in both childhood and adulthood to precipitate their first episode of depression than individuals who don't have the variant. According to Dr. Harkness, "This particular genetic makeup colors a young person's perceptions of the world so that they react to stresses in their environment much more strongly than do other people. There are potentially devastating consequences to their psychological well-being for the rest of their lives."

Dr. Harkness believes the research "holds promise for fully understanding the causes of depression, thereby opening the door to the development of even more effective pharmacological and psychological treatments." □

Text edited from *A new study: the onset of depression in young adulthood* by Dr. Kate Harkness in *moods magazine*, fall 2007.

NARSAD ... continued from page 4

Antidepressants & teen suicide risk

The back-story: In 2004 U.S. makers of antidepressants were ordered to add "black box warnings" to their labels to indicate that the drugs were associated with increased risks of suicidal thinking and behavior in young people.

2007 statistics revealed that the suicide rate among 10-24-year-olds had jumped by eight percent in 2004, the largest single-year rise in 15 years. Some psychiatrists are concerned that the sudden rise may reflect the impact the warning-label is having on young people with major depression, i.e. causing a decline in prescriptions among those who might have benefited from the treatment.

On a more positive note, a study published last fall indicates that combination therapy — antidepressant plus cognitive behavioral therapy — is more effective than medication alone in reducing the level of suicidal thinking and behavior in adolescents.

And from geneticists comes news that specific variations in two genes have been found linking suicidal thoughts that occur among some people taking the most commonly prescribed class of antidepressants. Depending on the particular mix inherited, these variants increased the likelihood of suicidal thinking two- to 15-fold.

The hope is that genetic testing may find more such markers and eventually help doctors identify patients on antidepressant therapy who are at high risk for suicidal thinking and who may need closer monitoring, alternative treatments and/or specialty care.

For more, much more, go to www.narsad.org □

