

The Support Network for Multiple Birth Families

Welcome...

Multiple Births Canada is pleased to announce the formation of a brand new chapter in Sault Saint Marie, Ontario. **Multiples are Us, SSM Multiple Births Association** has just registered as an official Chapter of MBC with 15 members strong. It is with a great deal of pleasure that we extend a big multiple birth welcome to our newest member chapter and we look forward to building a strong partnership between national and SSM-MBA in providing valuable support to multiple birth families in the Sault Saint Marie area.

We would also like to acknowledge the support and guidance provided throughout this process. Sheri Lockyer, Chapter Liaison, has been providing ongoing advice and information to the new chapter Chair, Karen Derochie. Vicki Riley in the business office is always quick to send out resources when required and many other volunteers have helped answer questions along the way. Let me extend a very big thank you for all the hard work and exceptional support provided.

Please extend a huge welcome to **Multiples are Us, SSM Multiple Births Association** and may you and your families enjoy the holiday season to its fullest.

Carrie Johnston
Chair
Multiple Births Canada

*Extracted from:
IC - BO-12-17-03-#1 - December 17, 2003*

Chapter Generosity...

MBC Chapter Barrie Parents of Twins and More made a generous donation to the Paediatric Department of The Royal Victoria Hospital in Barrie, enabling them to purchase a much needed infant scale. Shown here (photo to left) from left to right: Caryna Wilding-President, Vicki Riley-MBC Rep, Janice Crawford-Treasurer.



Project Updates...

Good Beginnings

December 17, 2003. VON Peel, in partnership with Multiple Births Canada, launched an exciting new program called "Good Beginnings". This innovative program aims to strengthen families, enhancing the probability of good parent-child bonding by providing information and practical help to overwhelmed families in the early months after the birth of their infant(s).

VON Peel, renowned for its tradition of working with new parents through community nurses and home support, has taken their commitment to a new level in creating the Good Beginnings Program, a volunteer-delivered program offering hands-on assistance to families of newborns who are feeling overwhelmed.

Caring volunteer visitors will facilitate the development of a secure, loving, and positive relationship between infants and their parents. They play an integral role in promoting healthy infant development by creating a stimulating environment, assisting with infant care, and/or helping parents participate in recreational activities in the community.

Referrals to the "Good Beginnings Program" will come from Multiple Births Canada, Peel Health's "Healthy Babies Healthy Children" program and VON nurses. Once referred, the Program Coordinators will match the parents with a trained volunteer who will visit the family each week for a minimum of 3 hours (6 hours for parents of multiple birth children) for a duration of three months.

In addition to an in-depth orientation and training session for volunteers, "Good Beginnings" will offer free monthly workshops covering a variety of topics relating to healthy infant/child development that will be open to parents as well. These valuable educational opportunities are made available to program participants thanks to collaboration with Multiple Births Canada, the Family Education Centre, the Early Years Literacy Consultants and Peel Infant Development

Extracted from IC - BO-12-17-03-#2

"Good Beginnings" has been made possible by funding through the Ontario Early Years Challenge Fund.

For more information on the "Good Beginnings" program, please contact Diane Myers at d.myers@multiplebirthscanada.org

Volunteer @ction Online

Work is steadily progressing on the new Volunteer Training and Orientation website. Through the dedicated guidance and coordination of Diane Myers, this project is in partnership with the Perinatal Bereavement Society of Ontario (PBSO) and will provide a valuable tool in orientating and training new and potentially new volunteers to the world of volunteerism with our respective organizations.

A special thanks goes out to all the individuals who have participated in filming the various video clips:

Mary Finer and her children	
Joanne McGlynn and her children	
Vicki Riley	Donna Launslager
Kimberley Weatherall	Diane Myers
Sheri Lockyer	Carrie Johnston
Lori MacEwen	Lynne Marwick
Lynda P. Haddon	Dr. Jon Barrett

A very special thank you to PBSO and Jan Pearce for allowing MBC to film at their offices in Markham, Ontario. Thank you to Jerome Richard Swanink (PrompterBuoy), Vince Ierulli (Director-12th Street Productions Inc.) and Owen Pearce (George Brown College), Diane Myers (Project Coordinator).

Mapping the Future

Materials produced as a result of the Mapping the Future project have been completed and disseminated to identified stakeholders of MBC. Included in this selection is a Professional PR pamphlet, Project Focus Group Findings, Stakeholders Package and of course, the long awaited and anticipated Chapter Handbook and Operational Guidelines.

Chapter Handbook & Operational Guidelines

Upon conclusion of the Mapping The Future project, every MBC chapter received a Chapter Handbook in August of 2003. This handbook is to assist new and experienced chapters in the daily operations of their chapter. We hope your executives have had a chance to review this handbook. We are requesting that chapters pass this handbook from President to President as your executive changes and your chapter grows.

In the future, sections will be updated or added and these portions will be sent to your chapter to be included in this binder. Positive or negative feedback regarding this handbook can be directed to the Business Office at office@multiplebirthscanada.org.

Report From National



The Support Network for Multiple Birth Families

Making a Difference Awards...

Submission deadline is March 15, 2004 - Don't delay!

Board & Volunteers...

If you have any questions please feel free to contact the Board of Directors at any time.

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Vice-Chair, Kim Weatherall
Treasurer, Carrie Johnston
Secretary, Lisa McInnes
Past President, Bonnie Schultz
Privacy Officer, Kim Weatherall
Privacy Officer, Carrie Johnston

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Director of Finance, Carrie Johnston
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Director of Information Management, Lisa McInnes

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Chapter Liaison, Sheri Lockyer
Clothing Sale Updates, Shelly Blizzard-Jones
Conference Liaison, Kim Weatherall
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makingadifference@multiplebirthscanada.org
marketing@multiplebirthscanada.org
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mmarketing@multiplebirthscanada.org
mmbookreviewer@multiplebirthscanada.org
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Online Purchasing...

Just a reminder that publications and memberships can be purchased on line. Ecommerce has been enabled using secure third party payment processing by Pay Pal. If you want to pick up some booklets, or renew your membership (not available for Affiliate membership), take advantage of the convenience of ordering from the comfort of your own home.

Watch for more Affiliate programs to be added to our website. Help support MBC by shopping at our Affiliates and click through from our site.

Thanks...

MBC would like to recognize one of many valuable volunteers. Without the help and support of numerous volunteers, Multiple Births Canada (MBC) would be hard pressed to reach its goal of providing literature, research, professional input, Multiple Moments, the Website and more as support to families across Canada.

If you would like to thank a special volunteer, be sure to nominate them for a "Making a Difference Award". There are so many special people that make a difference in our lives, it's one small way of thanking them!

Sustaining Members...

MBC would like to thank its sustaining members for your added support.

**Jennifer Brasch
Paula & Ron Clark
Georgina Dimopoulos
Isilda Dos Santos
Bonnie L. Schultz**

Donations...

MBC gratefully acknowledges the following donations:

- Monetary donation to the Loss Support Network and all the Little Angels - donated by Eileen M. Haddon
- Monetary donation to MBC in memory of Diane Myers father, George E.S. Eldridge - donated by Donna Launslager

Chapter Business...

New Fundraiser

Be sure to check out the inside cover of the **Quarterly Issue 1-2004 Multiple Moments** for information on a brand new fundraiser that will benefit chapters, MBC and the environment.

MBC Chapter Email Addresses

All MBC chapters have been assigned a specific yourchapter@multiplebirthscanada.org email address. You are invited to use this email address on your letterhead, newsletter or any other correspondence. It never has to change. It will forward ONLY to the email address that you provide to Multiple Births Canada. If there is a change in the email address you have provided, you MUST notify us of that change so we can change the forwarding. If you have further questions, please email the Business Office at: office@multiplebirthscanada.org

Your Link to MBC What is an MBC Rep?

What is an MBC Representative (Rep) and do you know who the MBC Rep is in your Chapter? Do your chapter members know what an MBC Rep is? Does your chapter have an MBC Rep?

The exact job description may vary from chapter to chapter, but the primary function of an MBC Rep is to give members information they might need about MBC. An MBC Rep is the link between the members and MBC.

The following page shows what a model MBC Rep job description is:



Report From National

The Support Network for Multiple Birth Families

MBC Representative Job Description

ROLE:

The MBC Representative acts as the liaison between their chapter and national. Ideally this person would be part of their local executive/Board of Directors possibly already holding the position of Vice-President or President. The MBC Representative sustains the relationship between Multiple Births Canada and their Chapter.

RESPONSIBILITIES:

- ensures up-to-date membership list with addresses and dues are sent to MBC Business Office prior to January 1st or expiry date;
- advises MBC Business Office of new members throughout the year (quarterly) and ensures appropriate dues are sent (Dues: MBC membership dues and Multiple Moments magazine subscription);
- encourages member subscriptions to Multiple Moments;
- ensures Report From National is distributed and/or available to all members either in print or electronically;
- advises MBC of Chapter significant events/photos to be shared in the Report From National;
- attends annual national conference, if financially possible, subsidized by chapter;
- when attending national conference, the MBC Representative must attend volunteer/chapter focused workshops where possible and report accordingly;
- receives and distributes the Information Circulars that are sent out regularly from MBC via email;
- keeps their chapter members aware of significant changes, updates, news, policy changes, etc. concerning MBC;
- acts as MBC spokesperson at the local level;
- in the absence of a delegate from their chapter at the annual national conference, the MBC Representative would ensure that all proxies are received at the Business Office by the appropriate date.

QUALIFICATIONS:

- MBC suggests this position be held by the Vice-President or President when necessary (ensures communication);
- be familiar with MBC policies, procedures, mission, goals and objectives;
- internet and email access.

All our volunteers are valuable, as an MBC rep, you provide an invaluable link to our members at the chapter level

Research Notices...

New National Institutes of Health Study Entitled:

PATHOGENIC STUDIES IN FAMILIES WITH TWINS OR SIBLINGS DISCORDANT FOR SYSTEMIC RHEUMATIC DISORDERS

A new unit of the National Institute of Environmental Health Sciences, called the Environmental Autoimmunity Group (EAG), has been established in Bethesda, Maryland at the National Institutes of Health (NIH), in the U.S. Department of Health and Human Services, to conduct pioneering research in understanding the genetic and environmental risk factors that may result in autoimmune diseases.

The EAG is currently enrolling families — in which an adult or child meets criteria for Rheumatoid Arthritis/Juvenile Rheumatoid Arthritis, Systemic Lupus Erythematosus, Systemic Sclerosis or Myositis — and in which a twin or sibling of the same gender, who is within 47 months of age, does not have any one of these 4 illnesses or another autoimmune disease. Subjects may enroll at the NIH Clinical Center in Bethesda, Maryland or in their local doctors' offices. Patients remain under the care of their personal physicians while participating in the study. There is no charge for study-related evaluations and medical tests at the NIH.

For information about the NIH Twin-Sibs Study please call:

1-800-411-1222 (For TTY: 1-866-411-1010)

IDENTICAL AND FRATERNAL TWINS NEEDED

Identical and fraternal twins age 19 and older are required for a new multi-centre study of how people respond to stressful events in their lives. Participants will be sent a questionnaire package to be completed at their convenience and returned by mail. The questions are short and will take about 3 hours to complete. All responses are kept completely confidential. Participants will receive a \$25 honorarium, their personality profiles, and regular updates on study results.

For more information about the study, please contact: Dr. Dana Thordarson
Toll-free: 1-866-822-0008
Email: thordars@interchange.ubc.ca

It is the responsibility of the family or individual interested in participating in a research initiative to make contact with the researchers. MBC only provides the means to advertise important research in multiple births.

International News...

The 11th International Congress on Twin Studies will take place July 2-4, 2004 at the Campus, University of Southern Denmark.

The Congress programme includes sessions on:

- Molecular genetics and twin studies - Recent advances - arranged by Leena Peltonen and Jeff Murray
- Paediatric aspects - arranged by Steffen Husby
- Controversy on obstetric issues - arranged by Jens Langhoff-Roos and Isaac Blickstein
- Statistical issues in twin studies - arranged by Ivan Iachine and Jacob Hjelmborg
- Psycho social aspects in the twin family - arranged by Elizabeth Bryan
- Twin studies on aging and longevity - arranged by Jim Vaupel, Matt McGue and Kaare Christensen
- Behavioural genetics - arranged by Dorret Boomsma
- Ethical issues - arranged by Jennifer Harris
- Sessions for Combo and Tamba
- Open sessions: complex disorders, immunology, PET scanning, language development, obesity, the metabolic syndrome, eating disorder, and dependence
- Open session: current developments and findings from twin studies

For more information, visit the website at: <http://www.icts2004.sdu.dk>

2004 MBC Conference...

Check out the MBC website for the 2004 Conference information and view your personal invitation to New Liskeard, Ontario. The conference planning committee is busy planning a program focussing on relationship building with our partners, with our children and with ourselves!

The registration form is now posted on the website and is also enclosed in Multiple Moments quarterly issue 4, 2003. For more information please contact the Registration Chair, Lori MacEwen at conference2004@multiplebirthscanada.org or Kim Weatherall, Conference 2004 Board Liaison at: conferenceliason@multiplebirthscanada.org

Don't forget to exercise your right to vote at the 2004 Annual General Meeting. If you are not attending the conference and AGM, you may assign your vote by completing a Proxy form and sending in or giving to your chapter representative to bring.

Your voice can make a difference!

Report From National



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Privacy Legislation - Important Information...

What does the Personal Information Protection and Electronic Document Act (PIPEDA) mean for Multiple Births Canada and its Chapters?

The following information about privacy legislation was extracted from:

Privacy 101: A Guide to Privacy Legislation for Fundraising Professionals and Not-For-Profit Organizations, Version 1

(http://www.ccp.ca/public_affairs/pdf/Privacy_101_A_Guide_to_Privacy_Legislation.pdf)

The MBC Board of Directors has begun to educate themselves on what impact this new legislation has for MBC as a national organization, for its individual chapters, its volunteers and members. The following information was extracted from the above-mentioned document to give you a sense of what the implications may mean to MBC, its chapters, its members and its volunteers. Because each chapter resides in a different jurisdiction it would be most beneficial for each of the chapters to do some additional research for your specific locations. The information provided here is only the very basics of the implications that it may have for the work we do as an organization and we urge you to take the time to visit the resources available to you for a more detailed explanation.

Please note: *The material provided in this article is for general purposes only and is not intended, nor should be construed as legal advice, opinion, or endorsed as lawful practice.*

There are various privacy and data protection laws in force across Canada. The federal government enacted the *Personal Information Protection and Electronic Document Act* (PIPEDA) in 2000. PIPEDA extended privacy protection to personal information collected, used and disclosed for commercial purposes in the private sector and voluntary sectors. Full application of PIPEDA goes into effect on January 1, 2004, although the Act already applies to certain federally regulated and inter-provincial transactions. For information on current application of PIPEDA to your organization's activities, check the website of the Privacy Commissioner of Canada (<http://www.privcom.gc.ca/>) or consult your legal counsel.

The Model Code for the Protection of Personal Information forms the backbone of the PIPEDA. The code was developed by the Canadian Standards Association and contains 10 principles to be respected. In brief, these are:

- 1) Accountability:** Organizations are responsible for all personal information under their control and remain responsible when personal information is processed by third parties on their behalf.
- 2) Identifying purpose:** Organizations are required to document purposes before they can collect and use personal information.
- 3) Consent:** Knowledge and consent of the individual are required to collect, use or disclose personal information.
- 4) Limiting collection:** The amount and type of information is limited to what is necessary for identified purpose.
- 5) Limiting use, disclosure and retention of personal information:** Information can only be disclosed or used for the purposes for which it was collected.
- 6) Accuracy:** Personal information has to be accurate, complete and as up to date as is necessary for the purposes for which it is to be used.
- 7) Safeguards:** Organizations must take steps to protect personal information from theft and loss, as well as unauthorized access, disclosure, copying or use.
- 8) Openness:** Organizations must provide the public with general information on their personal information protection policies and practices and must make it easy to identify and contact the person responsible for personal information protection.
- 9) Individual access:** Upon request, individuals must be informed of the existence, use and disclosure of all their personal information and be given access to that information. An individual has the right to challenge the accuracy and completeness of the information and have it amended as appropriate.
- 10) Challenging compliance:** An individual can challenge an organization's compliance to the code, and an organization must develop procedures to handle complaints.

In general, if an organization is operating under these 10 principles, it will tend to be in compliance with PIPEDA.

If you have any additional questions or concerns please feel free to contact our newly appointed Privacy Officers: Carrie Johnston chair@multiplebirthscanada.org or Kim Weatherall vice-chair@multiplebirthscanada.org

Volunteers Needed...

You could be part of the team!

Wouldn't you like to be part of the decision making body of our organization? While that task alone may seem ominous, there is nothing more rewarding than knowing that the time spent understanding an issue and making a decision benefiting all our members and the future of multiples is time well spent. There is no mistaking that there is work involved in sitting on the Board, but with a major project like Mapping the Future wrapped up, ideas are flowing for another project in order to start implementing and developing needed resources. This is an exciting time to be involved!

The main qualifications needed to sit as a Director are a keen interest in MBC, experience or knowledge of the portfolio for any given position, and preferably past experience at the regional Chapter level. Easy access to e-mail and comfort using technology to conduct business are also important.

What are you waiting for? Step up to the challenge!

Current volunteer opportunities within Multiple Births Canada include but are not limited to:

- **Director of Publications**
- **Director of Fund Development**
- **Director of Finance**
- **Director of Communications**
- **Director of Membership**
- **Special Needs Support Network Liaison**
- **Production Editor, Multiple Moments**

Contact the Chair, or any members of the Board of Directors for more information! If you do not see something above that catches your interest but you have time and skills to share, be sure to contact Kim Weatherall and let her know what areas you might be interested in. She can be reached at volunteers@multiplebirthscanada.org

Sign up to receive...

Get up to date news delivered straight to your email address.

Get the latest breaking news hot of the presses and keep informed of exciting news from Multiple Births Canada. Sign up to receive Report From National and regular Information Circulars. You do not need to be a subscriber of *Multiple Moments* to receive these mailings. Don't delay. To sign up, send a message to office@multiplebirthscanada.org, and ask to be put on the e-mail list!

CONFERENCE 2004 - June 3-6, 2004 - New Liskeard, Ontario