

# 22q & Friends



## 2017 Newsletter

### Inside you will also find...

- Clinical: healthy relationships
- Recent publications
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- 22q at the Zoo - June 11
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### And more...

### The DNA detective: Understanding family background and neuropsychiatric variability in 22q

Our newest addition to the team, graduate student Ania Fiksinski, is exploring an aspect of 22q11.2 deletion syndrome (22q) that's never been researched before. Providing better medical care to our 22q community means finding the roots of a problem before it gets bigger. This is what we want to understand: what genetic and family factors may protect our patients from some of the features typically associated with 22q, and how family members manage tough times when caring for an individual.

Participants will spend time with Ania and/or our research assistants, Alexandra Therond or Tracy Heung, with assessments related to learning and memory. We want to know how our patients and their families learn, whether they have relative strengths and weaknesses in certain areas, and how memory may be processed differently in 22q. They will also fill out questionnaires that explore how family members cope with challenges that can arise from being a caregiver.

We also ask participants to provide a blood sample - if we don't already have one from a previous appointment. Though only a small sample, the DNA (genetic material found in every cell) collected offers the chance to help us understand several mysteries. A person's genetic background, outside of the 22q deletion, can help explain the likelihood that someone develops anxiety, or is born with a heart defect.

As with every research study we do, we take time to sit with our participants and

answer any questions they might have. For example, we would explain that this study is completely confidential and private. No identifying information about individual people is ever presented. Every person who participates is giving a priceless gift - contributing to the knowledge about 22q that will help others with this condition and their families, now and for future generations.

Since we want to encourage participants to be part of our study, all costs related to travel and lunch will be covered. We will make sure that the time spent with us is as comfortable as possible.

Working with so many people with 22q over the years, we understand that each person is unique. We are still searching for the best way to help predict what lies ahead for our patients with 22q. Our ongoing 22q study may help us to predict medical problems and perhaps discover effective management sooner, giving our patients a better outcome and a brighter future. We would like to take this opportunity to say a big thank you to each and every one of our participants!

This part of our study started in January 2017, and we will continue to ask families to participate over the coming years. If you have any questions or would like more information about how to help with this study, you may contact us at the Clinic!

#### Investigators/study doctors:

Principal Investigator: Dr. Anne Bassett  
Study Coordinator: Ania Fiksinski, MSc.



Dr. Anne Bassett,

Director, CGRP &  
The Dalglish Family 22q  
Clinic

## Did you know...



- Most people with 22q do not inherit this condition from a parent. The genetic change usually happens as a new event. We do not yet understand what makes this genetic change happen.
- Every person (man or woman) who has 22q has a 50% (“50-50”) chance of passing this deletion on at every pregnancy.
- The word “syndrome” means a collection of clinical features each of which can be recognizable but that can vary from person to person.

## Hello and happy reading from all of us!

Hello again from the The Dalglish Family 22q Clinic and the Clinical Genetics Research Program (CGRP)! We hope you, your family and friends had a wonderful 2016. As we progress with our Clinic and research specializing in adults with 22q11.2 deletion syndrome (22q), we like to keep you up-to-date. As always, our goal is to continue to personally contact and hopefully see each of you in 2017! This newsletter is intended to share news and updates as well as help to answer some important questions about 22q.

Our program continues to see old friends and newcomers for our research studies in 22q. At the moment, we have seen about 300 adults with 22q and related conditions from across Canada.

We have seen more adults with 22q than any other single centre worldwide. Our collaborative research program works in conjunction with the Centre for Addiction and Mental Health (CAMH), the rest of the University Health Network (UHN) (Toronto General Hospital, Toronto Western Hospital, Princess Margaret Hospital), and the Hospital for Sick Children, as well as hospitals and clinics across the country. Our ambition is to continue to learn more about 22q and other genetic syndromes. Most importantly, we want to find out how to best manage the associated illnesses and conditions to help improve the long-term outcomes for people with 22q.

## Happy reading!

## Psychosexual knowledge and related issues in adults with 22q



Intimate relationships, sexual activity and pregnancy can be important parts of adult life for people with 22q. Challenges can arise in any of these areas, especially when a person has learning disabilities and difficulties with social judgment. How can we best support individuals in these important areas of their life?

Learning more about relationships and sexual health in people with 22q is a current focus of our social workers, Lisa and Pam. Researchers have found that people who have an intellectual disability (ID) tend to score lower on tests measuring sexual knowledge than people without ID. This lack of knowledge of basic sexual concepts

can increase the risk of victimization and issues related to healthy relationships and sexual consent. Despite these concerns, there is very little information about people with 22q, relationships and sexual health.

In spring 2016, we started using a clinical tool to assess the level of sexual knowledge and risky behaviours in adults with 22q, with and without ID. We hope this will help us and potentially other clinicians and educators to have better information about this important topic to give to patients with 22q and their families. It will also help us to identify needs for better counselling and educational programs about healthy relationships and sexuality.

To help us with this effort, during a regular visit at the Clinic our patients sit with one of our social workers in

## Psychosexual knowledge and related issues in adults with 22q11.2 deletion syndrome cont'd

a comfortable setting to discuss this important subject. The answers you give will be kept confidential. If you have any questions or would like to have information about this quality assurance project you may contact our research staff at:

The Dalglish Family 22q Clinic at Toronto General Hospital  
(416) 340-5145.



### Clinic awards 2015 - 2017

Please join us in congratulating the following Clinic members on their recognized achievements:

#### Junior Investigator Award - 2016

Our graduate (PhD) student, Ania Fiksinski, was awarded the Junior Investigator Award for the most outstanding clinical research presentation by a junior faculty member at the International 22q11.2DS Biennial Meeting in Sirmione, Italy, in July 2016.

#### UHN Centre for Mental Health Fellow Research Award - 2015-2016

Dr. Erik Boot received this award in 2016 for a second consecutive year. This acknowledges Fellows at UHN who have made outstanding contributions to the field of Mental Health. Dr. Boot returned to the Netherlands with his family at the completion of his fellowship but continues his 22q research and still visits us here.

#### Max Alexandroff Award – 2015-2016

Dr. Erik Boot also received the Max Alexandroff Award given by the Department of Psychiatry at the University of Toronto in June 2016 for his outstanding achievements as a Fellow.



Left to right: Dr. Jacob Vorstman, Ania Fiksinski, Dr. Anne Bassett

#### Mel Silverman Mentorship Award

Dr. Anne Bassett received the 2017 Institute of Medical Science (IMS) Mel Silverman Mentorship Award on May 3rd, 2017. This award is presented to an IMS graduate faculty member who has served as an outstanding mentor and role model for graduate students, and who has contributed in a significant way to the IMS graduate program. All candidates for this award are nominated by IMS graduate students.

Did you know...

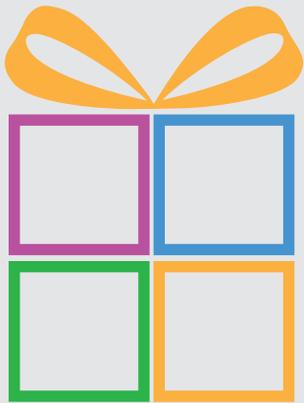


22q actually had a lot of different names before:

- DiGeorge syndrome
- Velocardiofacial syndrome (VCFS)
- Conotruncal anomaly face syndrome
- Opitz G/BBB syndrome
- Cayler cardiofacial syndrome

These names were given by different doctors who worked in specialized areas before we know they were all tied together by the piece missing on chromosome 22.

For more information, please visit our website: [www.22q.ca](http://www.22q.ca) and click on "Same Name Campaign".



## Donations

The most important donation is your generous participation in our research studies. Without your support, we could not hope to make advances in treatment or achieve medical breakthroughs for patients with 22q.

Donations from individuals or groups may be made to the Dalglish Family 22q Clinic. The donations go directly towards helping support our research initiatives and Clinic.

Your gifts are greatly appreciated and ensure we can keep going with our studies!

To donate online, visit our website: [www.22q.ca](http://www.22q.ca) and click "Donate"

All donors receive a taxable receipt.

## An inside look into The Dalglish 22q Clinic : staff members

### Dr. Anne Bassett: Director & Psychiatrist



Dr. Anne Bassett is the Director of the Dalglish Family 22q Clinic and the Dalglish Chair in 22q Deletion Syndrome. She is a psychiatrist and world renowned expert in the genetics of complex conditions - especially 22q. Dr. Bassett is also the Director of the Clinical Genetics Research Program at CAMH and a Professor of Psychiatry at the University of Toronto. She is a leader in an international group study of 22q and is the Medical Director for the International 22q Foundation. Dr. Bassett has been providing exemplary care to adults with 22q, their families and caregivers for many years.

### Dr. Maria Corral: Psychiatrist



Dr. Maria Corral completed her medical studies at the University of British Columbia. She worked for thirty years as a psychiatrist, educator and administrator until her retirement as Head of the Department of Psychiatry and Director of Medical Education at St. Paul's Hospital, Providence Health Care in June of 2014. She was also Vice-Chair of the Psychiatry Examination Board for the Royal College of Physicians

and Surgeons of Canada from 2011-2014.

Now living in Toronto, Dr. Corral is honoured to join The Dalglish Family 22q Clinic and its exemplary multidisciplinary team of clinicians.

### Dr. Elemi Breetvelt: Psychiatrist



Dr. Breetvelt is our new Clinical Fellow at the Dalglish Family 22q Clinic. His fellowship is supported by a generous gift of the Mukherjee family. Dr. Breetvelt has worked since 2008 as a psychiatrist at UMC Utrecht in the Netherlands, and has followed children, adolescents and young adults with 22q. Trained as an epidemiologist at Utrecht University, the main focus of Dr. Breetvelt's research is on the genetic epidemiology of psychiatric disorders, especially schizophrenia. He is interested in the factors that contribute to changes in social behaviour, and early factors that may indicate an increased risk of developing psychiatric illness.

### Lisa Palmer: Social Worker



Lisa graduated with a Bachelor of Arts degree in Psychology in 2010 and a Bachelor of Education degree in 2012. She completed a Master of Social Work degree at the University of Toronto in 2015.

## An inside look into The Dalglish 22q Clinic : staff members

Working with the Clinic team, Lisa assists patients and their families in examining challenges and concerns and in helping to find the best available community resources. She also continues to help our clinical research efforts.

### **Pam McFarlane: Social Worker**



Pam McFarlane is a Social Worker in the Dalglish Family 22q Clinic. She has over 25 years of experience working with the University Health Network in several areas of care. Working

with the Clinic team, Pam assists patients and their families in examining challenges and concerns and in helping to find the best available resources. She also facilitates groups and provides counselling and support as requested.

### **Samantha D’Arcy: Registered Dietitian**



As a Registered Dietitian at the Dalglish Family 22q Clinic, Samantha works collaboratively with patients and their families to create nutrition plans that fit their needs and lifestyle. In addition

to one-to-one patient care, Samantha is involved with group facilitation and patient and caregiver education as requested.

### **Radhika Sivanandan: Patient Flow Coordinator**



Radhika is likely the first person you will encounter when you come to the Clinic. She co-ordinates all appointments and ensures that all necessary documents are

available. Please feel free to contact her at the Clinic’s main number (416) 340-5145 if you have any questions or concerns regarding your appointments.

### **Ania Fiksinski: Graduate student**



Ania is a PhD graduate student from the Netherlands who obtained her Master’s degree in Clinical Psychology from the University of Utrecht in 2013. Since then she has been working as

a psychologist in the Department of Psychiatry at the University Medical Center in Utrecht, specializing in psychological assessment and treatment of children and adolescents with 22q. She has also been actively involved in academic research regarding the cognitive and psychiatric features of 22q.

Ania is currently pursuing a PhD degree with Dr. Bassett in a collaboration between the University of Toronto and its international partner university, the University of Utrecht.



### **Research and Other Staff**

**Gladys Wong:  
Coordinator/  
research analyst**

**Alexandra Therond,  
Tracy Heung, Fiona  
Fu:  
Research analysts**

**Greg Costain:  
Medical Genetics  
resident**

**Lily Van: Psychiatry  
resident**

**Spencer Van Mil,  
Sarah Voll Malecki,  
Judy Truong, Janis  
Chang, Enoch Ng:  
Medical students**

**Joanne Loo:  
Patient and family  
educational tool  
developer and  
website manager**

**Joelleann Forbes:  
Social work student**

## The Clinical Genetics Research Program (CGRP) at the Centre for Addiction and Mental Health (CAMH)

### 22q11.2DS International Consortium & more

The CGRP and The Dalglish Family 22q Clinic are part of an international group of scientists and clinicians working to better understand 22q. We are working with many other international leaders in the field, including those who are listed on the next page.

In 2015 we published the first international clinical guidelines for adult patients with 22q.

Through our major research efforts, we are interested in how 22q can affect the brain and behaviour, as well as heart and other conditions.

Many of our Dalglish Family 22q Clinic team members also have a role at CGRP at CAMH. Together we are all working on research that will help us understand 22q and related conditions, like heart defects, schizophrenia and learning disabilities.

#### Toronto, Ontario

**Dr. Anne Bassett,**  
Principal investigator  
& Director

**Dr. Eva Chow,**  
Research psychiatrist

**Gladys Wong,**  
Coordinator

**Chelsea Lowther,**  
Graduate student

**Greg Costain,**  
Medical Genetics resident

**Tracy Heung,**  
Research assistant

**Justin Graffi,**  
Research assistant

**Lily Van,**  
R1 resident in psychiatry,  
Clinical scientist program

**Spencer Van Mil,**  
Medical student

**Sarah Voll Malecki,**  
Medical student

**Janis Chang,**  
Medical Student

**Judy Truong,**  
Medical Student

**Enoch Ng,**  
Medical student

**Pak Yin Sin,**  
Undergraduate research  
student

### Research funding



We continue to submit several research grant applications every year. If and when these are funded, these grants support our research studies of 22q and of several other related conditions. Canadian funding tends to be modest so many grants are needed to support our advanced genetic studies and our research team. We have received funding from:

**National Institute of Mental Health**  
Four-year international collaborative  
operating grant, 2013-2017

**McLaughlin Centre Accelerator Grant**  
One-year operating grant, 2017-2018

**Canadian Institutes of Health  
Research (CIHR)**  
Five-year operating grant, 2012-2017

**Canadian Institutes of Health  
Research (CIHR)**  
Five-year project grant, 2016-2021

We are very grateful to these agencies for their research support!

## Collaborating doctors & researchers

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Along with the CGRP Team, there are many collaborating doctors and researchers who work with us locally and internationally on 22q and related research. They include:

### Ontario

**Dr. Candice Silversides,**  
Adult Cardiologist,  
Toronto, ON

**Dr. Erwin Oechslin,**  
Adult Cardiologist,  
Toronto, ON

**Dr. Hanna Faghfoury &  
Dr. Chantal Morel,**  
Medical Geneticists,  
Toronto, ON

**Christian Marshall, PhD  
&  
Stephen Scherer, PhD,**  
Geneticists,  
Toronto, ON

**Dr. Susan George,**  
Endocrinologist,  
Toronto, ON

**Dr. Danielle Andrade,**  
Neurologist,  
Toronto, ON

**Dr. Anthony Lang,**  
Neurologist,  
Toronto, ON

**Dr. Connie Marras,**  
Neurologist,  
Toronto, ON

**Janice Husted, PhD,**  
Epidemiologist,  
Waterloo, ON

### Canada

**Dr. Sarah Dyack,**  
Medical Geneticist,  
Halifax, NS

**Dr. Pamela Forsythe,**  
Psychiatrist,  
Saint John, NB

### USA

**Dr. Linda Brzustowicz,**  
Geneticist,  
New Brunswick, NJ

**Bernice Morrow, PhD,**  
Geneticist,  
Bronx, NY

**Donna McDonald-  
McGinn,**  
Director 22q Clinic,  
Children's Hospital of  
Philadelphia (CHOP)  
Philadelphia, PA

### Asia

**Dr. Brian Chung,**  
Medical Geneticist,  
Hong Kong SAR, China

### Europe

**Dr. Jacob Vorstman\*,**  
Child Psychiatrist,  
Utrecht, Netherlands

\*Soon to be moving to the  
Hospital for Sick Children  
in Toronto!

**Ann Swillen, PhD**  
Child psychologist,  
Leuven, Belgium

### South America

**Dr. Gabriela Repetto**  
Geneticist,  
Santiago, Chile

### Australia

**Linda Campbell, PhD,**  
Psychologist,  
Newcastle, Australia

## Clinic events

### Did you know...



- 22q may be more common than we once thought. An estimated 1 in every 2000-3000 babies are born with the deletion on chromosome 22.
- Treatable psychiatric illnesses are one of the most common features of 22q in adults. About 6 in every 10 adults with 22q have a treatable psychiatric illness.
- The characteristics of 22q occur along a spectrum. Some individuals have more distinct features that are more easily recognized. Others may not have the classic features. Genetic testing is the only way to confirm a 22q deletion.

### 22q at the Zoo

On June 5th, 2016, the 22q Deletion Syndrome Clinic at the Hospital for Sick Children (SickKids) and the Dalglish Family 22q Clinic co-hosted the 4th annual 22q at the Zoo event. The focus of the day was for individuals with 22q, their families and Clinic staff to socialize, network and raise awareness of 22q in the community. Participants also had the chance to go on walks through the zoo, join in fun activities with their friends and families and win great prizes.

In 2015, a record 115 cities participated in 22q at the Zoo! We are looking forward to the next event on Sunday, June 11th, 2017. 22q at the Zoo is held each year all around the world as part of the 22q at the Zoo Worldwide Awareness Day, organized by The International 22q11.2 Deletion Syndrome Foundation.

### Peer Support Groups

The Dalglish Family 22q Clinic holds peer support groups for individuals with 22q and their parents or caregivers. We facilitate two groups, which each run for about 90 minutes:

- A group for parents or caregivers to talk to other parents about concerns, challenges, and successes.
- A group for our adult patients to meet each other, participate in some fun exercises and to discuss topical subjects with staff facilitation.

For those parents and caregivers unable to attend in person, an on-line weblink is offered to give access to the group from home.

The next group will be held soon, so stay tuned for more information!

### 22q Family Conference

On November 12th and 13th, 2016, the

3rd annual 22q11.2 Family Conference was held at SickKids in Toronto. This conference gave individuals with 22q and their families the chance to learn more about 22q and to meet other families sharing their same experiences.

Information sessions for parents, teens and young adults were offered on topics such as:

- Health and Nutrition
- Impact on Siblings
- Mental Health Needs of Teens
- Navigating the Education System

Participants enjoyed the keynote presentation from Quinn Bradlee, founder of Friends of Quinn, an online community for individuals with 22q, and many other inspiring speakers.

We hope that you will join us on November 11th & 12th, 2017 for the 4th annual 22q11.2 Family Conference. Check back in summer 2017 for details about registration at [22qfamilies.org](http://22qfamilies.org).

### Transition Program

Becoming an adult is a process that sparks change in everyone's lives, including individuals with 22q. "How will 22q symptoms affect my life as I become an adult?" This is a common question for many of our patients and their families.

The Dalglish Family 22q Clinic, in collaboration with The SickKids Good 2 Go Transition Program and The SickKids 22q Deletion Syndrome Clinic, offers the 22q Transition Clinic several times per year. This full day program gives individuals with 22q information about adult care and shows how we make a smooth transition from the 22q Clinic at SickKids to our Dalglish Family 22q Clinic at Toronto General Hospital.

We look forward to holding our next 22q Transition Clinic on July 18th, 2017, so look out for more information soon!

## Healthy snacking

If you find yourself tired and hungry between meals most days, a healthy snack is a great way to give you more energy. Follow the chart below to create a perfect healthy

Pick <b>ONE</b> food from this box:		Pick <b>ONE</b> food from this box:	
A fruit		A dairy product	
	Size of your fist 	one cup	Size of two fingers 
A vegetable			
	Size of your fist 	Size of your fist 	
A whole grain		A meat or meat alternative	
	one slice	Size of your palm 	2 eggs
		two spoons 	
	Size of your fist 	Size of your palm 	

## Enjoying the Internet safely



The Internet is a great place where you can meet new people, stay in touch with friends and find a lot of information. To keep it a great place, you also have to know some of the dangers of the Internet. Some “online friends” may not be who they seem to be and can try to take advantage of you. Read the following tips to be as safe as possible:

1. Use a screen name instead of your real name whenever possible. Never give out your full name, address, birth date, phone number, name of your school or workplace.

2. Use strong passwords (a mixture of letters and numbers, upper and lower case) and don't tell your password to anyone else (except your parents or caregivers).

3. Never give out your social insurance number, credit card numbers, PINs or banking information.

4. Never send naked or other inappropriate pictures of yourself to anyone.

5. If you plan to meet with someone you met online, ask for your parents' (or caregiver's) permission, tell someone you trust and take someone with you. Always meet in a public place such as a coffee shop.

6. Tell your parents (or caregivers) if something does not feel right. For example: if someone wants to meet with you alone, asks to see a naked photo of you, asks for money, or asks questions that make you feel uncomfortable.

We want your input!



We want to create newsletters that interest you. What information would you like to see in our next newsletter?

Perhaps you have questions for us about 22q or another genetic syndrome.

Maybe you have a comment or story to tell us. We want to hear from you so that we can make each and every newsletter more helpful and enjoyable to read.

We invite you to email us at [22q@uhn.ca](mailto:22q@uhn.ca) or fax your comments to us at (416) 340-5145!

## New publications



Did you know...



- Most people with 22q are missing a piece of genetic material (DNA) that is about 3 million DNA building blocks long, on one copy of chromosome 22. This region contains about 46 genes that code for proteins. We do not yet know what all of these genes do.
- Individuals with 22q may have thyroid problems. The thyroid may be under or over active. Regular thyroid testing can help to identify a thyroid problem so that effective treatment can be started.

We are excited to announce important publications on 22q since our last newsletter. These would not be possible without your generous contributions to our research. You are helping people with 22q worldwide!

Some of our recent publications include:

### **Obesity in adults with 22q11.2 deletion syndrome.**

*Voll SL, Boot E, Butcher NJ, Cooper S, Heung T, Chow EWC, Silversides CK, Bassett AS: Genetics in Medicine, 2016 (doi:10.1038/gim.2016.98)*

This study compared the heights and weights of adults with 22q to the Canadian population. Starting in the 19-24 age group, on average people with 22q had higher rates of obesity whether they were or were not taking medications that can increase the risk for weight gain.

### **Internet safety issues for adolescents and adults with intellectual disabilities**

*Buijs PCM, Boot E, Shugar A, Fung WLA, Bassett AS: Journal of Applied Research in Intellectual Disabilities, 2016 (doi:10.1111/jar.12250)*

This brief report looked at some potential challenges of internet safety for adolescents and adults with 22q. Examples of particular dangers were presented, and safety interventions and next steps for doctors and clinicians were discussed.

### **The importance of copy number variation in congenital heart disease**

*Costain G, Silversides C, Bassett AS: Genomic Medicine 1, 16031, 2016 (doi:10.1038/npjgenmed.2016.31)*

This review article looked at the contribution of genome-wide rare copy

number variation (CNV) to congenital heart disease (CHD). Prevalence of CHD in people with CNV was discussed, as well as clinical and research advances paving the way for whole-genome sequencing to understand the genetic basis for CHD in the future.

### **Whole-genome sequencing suggests schizophrenia risk mechanisms in humans with 22q11.2 deletion syndrome.**

*Merico D, Zarrei M, Costain GA, Ogura L, Alipanahi B, Gazzellone MJ, Butcher NJ, Thiruvahindrapuram B, Nalpathamkalam T, Chow EWC, Andrade DM, Frey BJ, Marshall CR, Scherer SW, Bassett AS: Genes Genomes Genetics 5:1-9, 2015 (doi: 10.1534/g3.115.021345)*

This research explored how rare changes outside of the chromosome 22q region might affect the risk for schizophrenia in people with 22q. The study used the most advanced technology to study potential approaches that would best find these genetic changes. This small study showed the value of this strategy.

### **Autism spectrum and psychosis risk in the 22q11.2 deletion syndrome. Findings from a prospective longitudinal study**

*Fiksinski AM, Breetvelt EJ, Duijff SN, Bassett AS, Kahn RS, Vorstman JA: Schizophrenia Research. 2017, in press*

This research investigated whether Autism Spectrum Disorders (ASDs) in individuals with 22q are actually associated with an increased risk for development of schizophrenia, or whether psychotic disorders and ASDs may arise independently. The answer was that they are independent conditions.

## Presentations



Each year we participate in several presentations on 22q and other related conditions. Some of our recent presentations relating to 22q include:

### **Society of Biological Psychiatry Annual Scientific Convention**

*Atlanta, Georgia, USA May 14, 2016*

At this annual meeting, Dr. Bassett presented along with Dr. Erik Boot and other 22q researchers on 22q as a valuable model for understanding schizophrenia, Parkinson's disease and other neuropsychiatric disorders. The presenters demonstrated how early changes to the brain can be identified in individuals with 22q, which may be able to help us find pre-diagnostic signs of disease and new targets for treatment.

### **Schizophrenia Society of Canada National Conference**

*Halifax, Nova Scotia October 27, 2016*

Dr. Bassett presented as the keynote speaker at this conference, delivering a talk about the clinical application of genetics for schizophrenia. She detailed clinical genetic testing and what the current standards of care are, and gave practical examples of how this relates to individuals with 22q.

### **10th Biennial 22q11.2 Deletion Syndrome International Meeting**

*Sirmione, Italy July 2016*

At this international 22q meeting, Dr. Bassett presented on rare copy number variations in 22q with and without schizophrenia. Dr. Boot presented on movement abnormalities in 22q. Clinic social worker Lisa Palmer presented on the "diagnostic odyssey" of patients with 22q and her work on attempting to better understand psychosexual knowledge in people with 22q. Past, current and future students and trainees Dr. Elemi Breetvelt,

Ania Fiksinski, Sarah Voll and Nancy Butcher (pictured below) also presented on 22q!



### **Grey Bruce Health System Grand Rounds**

*Owen Sound, Ontario April 14-15, 2016*

At two presentations in Owen Sound and nearby Walkerton, Ontario, Dr. Bassett and Dr. Boot presented about 22q, its prevalence, features and new advances in research to clinicians, community workers and educators, and the general public.

### **3rd Annual 22q Family Conference**

*Toronto, Ontario November 12, 2016*

At this conference geared towards patients and their families, Clinic social worker Lisa Palmer presented about personal advocacy, consent and respect. Clinic dietitian Megan Morrison presented about nutrition and exercise.

### **Ontario Police Presentation**

*Richmond Hill, Ontario April 7, 2017*

Clinic social worker Lisa Palmer and dietitian Samantha D'Arcy presented at the York Region Police headquarters to a group of police officers across Ontario who work in schools to educate about safety issues. They presented information about 22q and gave tips on how to communicate with people with 22q in the context of law enforcement and safety issues.

## Further Reading

Our Clinic has published a number of pamphlets recently that specifically address common concerns for people with 22q during the transition from adolescence to adulthood. Some titles include:

"Alcohol"

"Mental Health"

"Sexual Health"

"Internet Safety"

"Healthy Eating"

"Emergency Preparedness"

To read, please visit our website: [www.22q.ca](http://www.22q.ca)

and click on "Resources" and then "Pamphlets generated by our Clinic".

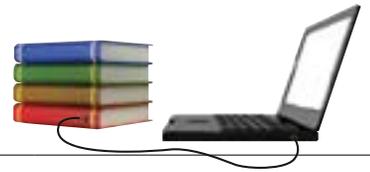
## Sending out a warm Thank You!

Recently we received the gift of some beautiful crocheted bracelets from one of our very own patients, who wanted to express her gratitude for our help.

Thank you so much!



## Online resources



Here are some websites that we hope you will find helpful about 22q and related issues:

### **www.22q.ca**

#### *The Dalglish Family 22q Clinic:*

Provides up-to-date information about our Clinic, including specialized services to help patients and families.

Information includes:

- Quick facts about 22q
- Directions to our Clinic
- Referral information
- Further reading for doctors

... and much more!

### **www.22q.org**

#### *International 22q11.2 Deletion Syndrome Foundation:*

Focuses on bringing awareness and support to individuals affected with 22q and their families.

### **www.schizophrenia.ca**

#### *Schizophrenia Society of Canada:*

Information for patients and families affected by schizophrenia, including treatment, daily living and advocacy.

### **www.cachnet.org**

#### *Canadian Congenital Heart Network:*

The learning centre contains

information and resources for adults who were born with a heart defect.

### **ONLINE RESOURCES: Healthy Sexuality**

For those planning a pregnancy or who are currently pregnant.

### **www.sexandu.ca**

This website offers information on sexual health for teens, adults, parents, teachers and health professionals.

### **www.motherisk.org**

Please see the Women, partners, family and friends section of this website. Motherisk provides information on taking medications, street drugs, or alcohol during pregnancy.

### **www.marchofdimes.com**

Please see the Pregnancy and newborn section. The March of Dimes is an excellent source of information for women who are planning pregnancy or are currently pregnant.

### **www.teenhealthsource.com**

This website is a way for young adults to learn more about sexual health and relationships.

# In Memoriam



Sadly, over the decades and very recently, we have lost members of our 22q family. They will never be forgotten and remain close to our hearts.

Their research contributions live on, and through this knowledge they continue to help others with 22q. They are included in all of our studies and their generosity will further advance the care of individuals with 22q throughout the decades to come.

They are true angels!

If you or your friends wish to make a donation in memory of someone special, please visit our website at [www.22q.ca](http://www.22q.ca) and click "Donate" or there is always regular mail to:

The Dalglish Family 22q Clinic, Toronto General Hospital,  
200 Elizabeth Street, Toronto, Ontario, M5G 2C4.

You can also call us for the option that suits you best.

## Giving back to the 22q community

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Over the years, with the help of our patients, families and researchers around the world, we have come far in learning about how to optimize care for individuals with 22q. Hundreds of patients and families have already participated by donating their time and blood sample. We also have very precious tissue donations from some of our patients who have passed away, that are helping us to understand more about all stages of the life cycle of 22q. All of our advances rely on the continued contributions of the amazing patients, families and caregivers who we see at our Clinic.

When our patients and families ask, “How can I help support other people with 22q?”, the answer is to get involved with research. We encourage patients and families to ask us what new research we are working on. We are happy to explain any of our ongoing and new studies and collaborations.

Every person with 22q can help! A special group are those who are doing especially well. These individuals can help us understand how well people with 22q can do, and can shed light on the secrets of good health in 22q.

We wholeheartedly appreciate everyone who has already given to the 22q community by participating in research. This is a gift that is improving healthcare for people with 22q – every day in our Clinic and around the world, and will do for many years to come.

### Contact us!



We are grateful to everyone who has donated their time for our 22q studies, and we hope that you will join us in the newest parts of our studies. All of the progress we are making is because of you!

As our studies progress, we need to maintain an up-to-date and accurate picture of your health status. We may contact you for updates on your family history and health status in the near future. Ideally, we like to see everyone with 22q once per year. This will also help you stay up-to-date on information about 22q.

#### **The Dalglish Family 22q Clinic Toronto General Hospital**

8 NU (Norman Urquhart), Room 802  
(8th Floor)  
200 Elizabeth Street  
Toronto, Ontario M5G 2C4  
Phone: (416) 340-5145  
Fax: (416) 340-5004  
E-mail: [radhika.sivanandan@uhn.ca](mailto:radhika.sivanandan@uhn.ca)

Please call or email Radhika for an appointment if we haven't seen you in a while!

#### **Clinical Genetics Research Program (CGRP) Centre for Addiction and Mental Health**

33 Russell Street, Main Building, 1st Floor  
Toronto, ON M5S 2S1  
Phone: (416) 535-8501 x 32731  
Fax: (416) 535-7199  
E-mail: [gladys.wong@camh.ca](mailto:gladys.wong@camh.ca)

Please call Gladys for an appointment if we haven't seen you in a while!