



A Day in the Life of NF1 2010 Symposium

April 9 & 10, 2010
Richmond, BC

Presented in partnership:



Dear Friends,

On behalf of the NF Canada Board of Directors and the BC Neurofibromatosis Foundation, I take great pleasure in inviting you to the most important event of 2010.



In Vancouver on the 9th and 10th of April 2010, NF Canada and BCNF are hosting the first ever national symposium on NF1. This represents an important milestone in our endeavour to increase awareness of NF and to reach the NF-affected population with information about recent research into the treatment and management of the condition.

With a terrific line up of speakers from Canada, the US and Europe (see schedule for details), our goal is to bring together families affected with NF and researchers to share information and experiences in the beautiful setting of Vancouver.

We encourage you to invite your physician, your child's teacher, your employer, your child's caregiver, grandparents, friends, and anyone else who needs to know more about NF.

This two-day symposium will be an excellent opportunity for you to learn about the new advances in NF1 research, meet with individuals and families from across Canada, network with experts in the field and to share your experiences with NF.

Friday, the more formal part of the symposium, is mostly sit and listen lectures ending with an opportunity to socialise at a gala dinner with guest speaker comedian David Roche. Saturday offers a less strenuous day in which you will meet two outstanding human beings: the dedicated Dr. Vincent Riccardi and the inspirational Reggie Bibbs. The day ends with an opportunity to share life experiences.

I am looking forward to meeting you in Vancouver in April at what promises to be a most stimulating and inspiring event! Please join us!

A handwritten signature in black ink, appearing to read 'Ron Turley'.

Ron Turley, President
NF Canada

We gratefully acknowledge our funders for their support of the symposium.



NF Canada
PO Box 5055 Victoria, BC V8R 6N3
Toll-Free: 1-888-986-3876
Email: office@nfcanada.ca
Website: www.nfcanada.ca



BC Neurofibromatosis Foundation
PO Box 5339 Victoria, BC V8R 6S4
Toll-Free: 1-800-385-2283
Email: info@bcnf.bc.ca
Website: www.bcnf.bc.ca

Thursday, April 8th, 2010

5:00pm to 8:00pm

Registration & Welcome Reception

Friday, April 9th, 2010

7:30am to 8:50am

Registration and Hot Buffet Breakfast

8:00am

Child Care Centre Opens

8:30am to 8:45am

Opening Ceremonies and Remarks

8:45am to 9:00am

Key Note Speaker: Kim McGinn
My Life with NF

9:00am to 10:00am

Session A1
Progression of NF1 over the Lifespan
Dr. Gareth Evans

10:00am to 11:00am

Session A2
NF1 and Dermatology
Dr. Pierre Wolkenstein

11:15am to 11:30am

Coffee Grab-n-Go

11:30am to 12:30pm

Session A3
NF1 and Learning Disabilities
Dr. Eric Legius

12:30pm to 1:30pm

Lunch Break

1:30pm to 2:00pm

NF Canada AGM

2:15 to 3:15pm

Session A4
Vascular Issues in NF
Dr. Jan Friedman

3:15pm to 3:30pm

Coffee Grab-n-Go

3:30pm to 4:30pm

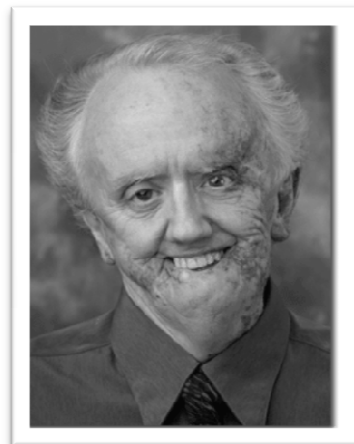
Concurrent 'B' Sessions

4:30pm

Child Care Closes

6:00pm to 10:00pm

Dinner and entertainment with
Comedian David Roche



Join us for a
**Social Dinner and Comedy
Show**

*Featuring the talented and
inspirational comedian
David Roche*

**Friday, April 9, 2010
6:00pm to 10:00pm**

Tickets: \$50

David Roche is an internationally known performer, speaker and author who has turned the experience of a congenital facial disfigurement from a source of personal shame to one of pride and inspiration. Come celebrate life with NF as we wine, dine and laugh the night away!



Spotlight on Kim McGinn
My Life with NF

Friday Key Note Presentation

This presentation will explore the experience of living your life with NF. Keynote speaker **Kim McGinn** has lived knowingly with NF for the majority of her life. She has worked as a manager of a group home for three developmentally challenged people for the last 12 years.

Session A1 : The Neurofibromatoses: Risks and New Hopes

Dr. Gareth Evans left the Army as a senior registrar in Paediatrics and joined the team at St Mary's in February 1990 as a senior clinical research fellow in cancer genetics. He successfully implemented genetic testing programmes for Familial Adenomatous Polyposis, Familial Breast Cancer and Hereditary colorectal cancer. His special interests are families with Neurofibromatosis Type 2 and he runs a monthly multidisciplinary clinic for management of families with this condition. He holds an NIHR programme grant investigating genetic screening in breast cancer. His major charity commitment is to the national Neurofibromatosis Association, Genesis, and Breast Cancer Campaign. He is chair of the Scientific advisory board of Genesis and deputy chair of BCC.



**Session A2: What's New in the Management of Neurofibromatosis 1?
The View Point of a Dermatologist**

Dr. Pierre Wolkenstein is a Professor of Dermatology, and has been the Coordinator of the National French Referral Center for Neurofibromatoses since 2004. He is the President of the French Society of Dermatology.



The impact of neurofibromatosis 1 upon quality of life will be addressed, the different possibilities of corrections, the identification of clinical severe phenotype.

Session A3: NF1 and Learning Disabilities

Dr. Eric Legius is a Professor in Medical Genetics with both clinical activities and research in the neurofibromatosis type 1 field.



Children with NF1 and NF1-like syndromes have frequent learning disabilities resulting from an overactive RAS-pathway in the brain. This opens up possibilities for treatment of learning disabilities.

Session A4 : Vascular Issues in NF

Dr. Jan Friedman is a medical geneticist who has been involved in clinical and epidemiological research regarding neurofibromatosis for more than 20 years. His current research interests include cardiovascular disease and tumour growth in people with NF1.



The most frequent causes of death are the same in people with or without NF1 – cardiovascular disease and cancer – but the average person with NF1 dies about 15 years earlier than the average person without NF1. Understanding the nature of neurofibromatosis-associated cardiovascular disease and cancer will provide opportunities to prevent premature death in people with NF1.

**B Sessions: Running Concurrently Friday, April 9, 2010
3:30pm to 4:30pm**

Session B1: Effects of the NF1 Gene on Bones

Kimberly Jett is a Ph.D candidate at the University of British Columbia. She has been studying NF1 for the past 2.5 years. She has been involved in studies of NF1 bone abnormalities and NF1 vasculopathy.



This presentation will give an overview of the bone abnormalities commonly found in individuals with NF1, the effect of the NF1 gene on bone and what we know so far, current research, and future research.

Session B2: Speech Characteristics of NF1

Dr. Penelope Bacsfalvi has been a practicing clinician for 14 years. Her various roles as a SLP include researcher, university instructor & advisor, clinician, and private consultant.

This talk will explore early intervention and areas of delay known to be present for individuals with NF1 (which include: speech, language, cognition, literacy, velopharyngeal insufficiency as well some question of ADHD). The best course of action in each of these domains will be discussed in this presentation.

Session B3: Reproductive Issues in NF1

Dr. Linlea Armstrong is a Clinical Assistant Professor in the Provincial Medical Genetics Programme. She is involved in genetic counselling, teaching, planning of curriculum at the UBC medical school, and research. She works at the BC Women's and Children's Hospitals, and at the BC Cancer Agency. She has a particular interest in hereditary tumour syndromes. She completed her residency at the University of Ottawa, and her MD at UBC.



Saturday, April 10th, 2010 Agenda

7:30am to 8:30am	Continental Breakfast	
8:00am	Child Care Centre Opens	
8:30am to 8:45am	Opening Remarks, Announcements	
8:45am to 9:30am	Keynote Presentation The New Von Recklinghausen Disease: Beyond Ras	Dr. Vincent Riccardi
9:30am to 10:00am	Session C1 Just Ask	Reggie Bibbs
10:00am to 11:00am	Session C2 Trust it or Trash it?	Patricia Birch
11:15am to 11:30am	Coffee Grab-n-Go	
11:30am to 12:30pm	Session C3 Coping with Chronic Sorrow	Nancy Makela & Susan Wood
12:30pm to 1:30pm	Lunch Break	
1:30pm to 2:15pm	Session C4 Alternative Health Care	Dr. Tanya Gee
2:15pm to 2:30pm	Coffee Grab-n-Go	
2:30pm to 3:30pm	Panels Panel 1: Adults with NF Sharing their Experiences Panel 2: Parents and Youth with NF Panel Sharing their Experiences	
3:30pm to 3:45pm	Closing Remarks Child Care Closes	

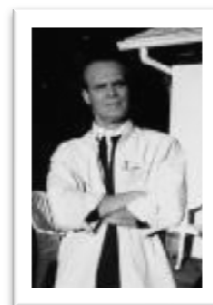
Spotlight on Dr. Vincent M. Riccardi

The New Von Recklinghausen Disease: Beyond Ras

Saturday Keynote Presentation

Much current research on NF1 focuses on cancer and the Ras oncogene, often ignoring the fact that this disorder is more than cancer and more than Ras. I will focus on the non-cancer aspects of NF1 and emphasize other genetic and metabolic considerations, particularly the S100 proteins, energy metabolism and oxidative stress.

Dr. Vincent M. Riccardi, MD began working on Neurofibromatosis in February 1972 and has used his skills as a clinical geneticist and cell biologist to explore how the disorder causes clinical problems and is able to teach us about general biology. He has been on the faculty of several medical schools, most recently that of UCLA. He has seen more than twelve hundred persons with NF in one form or another and has published more than a dozen or so articles, primarily about NF1 or von Recklinghausen disease.



C Sessions Saturday, April 10, 2010

Session C1: Just Ask!

Reggie Bibs lived most of his life “missing out on what life had to offer.” In his talk, Reggie will talk about living with NF, and enjoying life. You can do the same!



Session C2: Trust it or Trash it?

When you hear about a new treatment for NF, or new information on preventing symptoms, how do you know if it is the Real Deal ...or just snake oil? We'll discuss a web tool from Genetic Alliance that might help you to make that decision.

Patricia Birch has been lab manager and researcher at the UBC NF research lab since 1990 and has been involved in the NF community for nearly 20 years.



Session C3: Coping with Chronic Sorrow

We all experience various kinds of loss in our lives. Most often society expects us to follow the five stages of grieving beginning with denial and ending with acceptance. But what about those who experience an ongoing sense of loss and grieving that re-emerges throughout their lives? It is called Chronic Sorrow and we will discuss what that can mean to you.

Nancy Makela is a nurse with experiences in both the hospital and community setting. For the last 15 years she has been involved in a variety of research projects, including one of her recent projects, exploring the many challenges that parents of children with disabilities must endure. **Susan Wood** is the parent of a teen son with NF. She is currently the Program Coordinator for the BCNF and also a founding board member of NF Canada.



Session C4: Alternative Health Care

The goal for this presentation is to inspire each person to create a healthy foundation for overall health. We will look at the basic needs of the body, the importance of relaxation, the power of thoughts and words. Come with an open heart and an open mind.

Dr. Tanya Gee inspires her patients to seek health and wellness through the holistic practice of Traditional Chinese Medicine (TCM). Dr. Gee is a graduate of the Vancouver International College of Traditional Chinese Medicine 1996, completed her post-graduate studies and clinical practice in China and holds the highest rank of her profession in BC as a Registered Doctor of Traditional Chinese Medicine.





2010 Symposium Registration Form



Register online now at www.nfcanada.ca

Last Name _____ First Name _____ Centre/Organisation _____

Address _____ City _____ Province _____ Postal Code _____

Home Phone _____ Work Phone _____ Email _____

Will you require onsite child care? Yes No
If so, please provide the following information: _____

Name(s) of child/children _____

Age(s) _____ Affected with NF1? Yes No

Allergies or medication _____

From the following choices, please select which describes you:
 Adult with NF1 Parent of a child with NF
 Health care professional Teacher
 Care giver
 Other _____

Please choose one of the concurrent sessions to attend on the afternoon of Friday, April 9, 2010 (see pages 3 & 4 for descriptions)

- B1 Effects of the NF1 Gene on Bones
- B2 Speech Characteristics of NF1
- B3 Reproductive Issues in NF1

Fees

Registration	Early Bird Fee	Regular Fee 2 Days	Saturday only
Adult (13 or older)	\$125	\$175	\$75
Child (age 3-12)	\$75	\$100	\$55
Professional	\$225	\$275	\$140
Friday night Dinner & Comedy Show ticket:	\$50		

Payment:	Registration Fee \$
	Dinner Ticket \$
	TOTAL \$

Payment Methods:

Mastercard VISA Cheque Money order

Card # _____

Expiry: ____/____

Name on Credit Card _____

Early Bird Deadline:

To qualify for the Early Bird Registration Fee you must submit your registration and fee to the office on or before **February 26, 2010 at 5pm**

Please send your registration and payment to:

Mail: NF Canada
PO Box 5055
Victoria, BC V8R 6N3
250-743-2027

Fax: _____

Questions? Call: Alison Eagles, Conference Coordinator
p: (604) 872-7158
e: nfconference@alison eagles.ca

Refunds

There will be no refunds for cancellation.

Register online: www.nfcanada.ca



Getting to Richmond

By Air

The Best Western Richmond Hotel and Convention Centre is just 10 minutes from the Vancouver International Airport, and provides complimentary shuttle service from the airport to the hotel. The shuttles depart from the airport every 30 minutes at 10 minutes past the hour and 20 minutes to the hour.

Air Canada / Air Canada Jazz

Tel: 1-888-247-2262

www.aircanada.ca or www.flyjazz.ca

WestJet

Tel: 1-800-538-5696,

www.westjet.com

By Coach

Greyhound serves most communities in the province. Call your local Greyhound station for more information on times and fares from your area to Richmond.

Public Transit

If you are travelling by public transit, you can get detailed information on transit schedules in the Richmond area by calling TransLink at 604-953-3333 or www.translink.bc.ca

By Car

Located on Westminster Highway, the Best Western Richmond Hotel and Convention Centre is easily accessible by car or public transit. If you are driving, there is pay parking in the hotel parking lot for delegates during the symposium

Travel Stipends

Limited travel stipends are available. Please contact the NF Canada office for more information.

P: 1-888-986-3876

E: office@nfcanada.ca



Host Hotel:

Sheraton Vancouver Airport Hotel

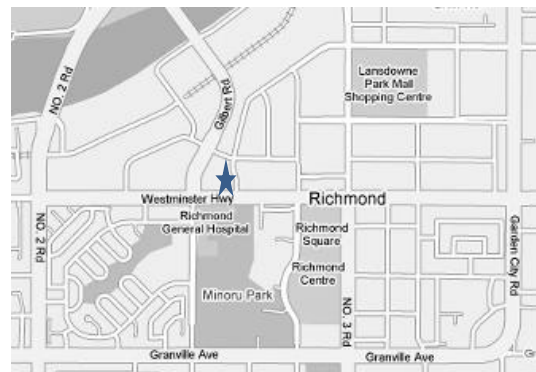
7551 Westminster Highway

Richmond, BC V6X 1A3

A special discounted group rate of \$159 is available for symposium attendees.

Please reserve your hotel room directly with the hotel reservations department at 1-800-663-0299 or email reservations@richmond-hotel.ca.

To ensure individual attendees receive the special rate quoted above; they must identify themselves as a participant attending the NF CANADA SYMPOSIUM and reservations must be made by March 10th to receive the discounted rate.



Attractions

Stanley Park

Enjoy picnic areas, playgrounds, walks or bike ride on the seawall take a horse-drawn carriage ride!

<http://vancouver.ca/PARKS/parks/Stanley/>

Vancouver Aquarium

Visit Canada's largest aquarium.

www.vanaqua.org

Capilano Suspension Bridge

This attraction takes you to the natural splendor of rainforest trails through magnificent evergreens and the unique perspective of Treetops Adventure.

www.capbridge.com

Watermania

Watermania offers a complete aquatic and fitness experience under one roof. Including wave pool and water slides.

www.richmond.ca/parksrec/pools/watermania.htm

Gateway Theatre

Around the World in 80 Days will be playing April 7th to 24th. Buy your tickets by calling the box office at (604) 270-1812 or online at www.gatewaytheatre.com

**Please inquire with the concierge for more information about local attractions, restaurants and shopping.*