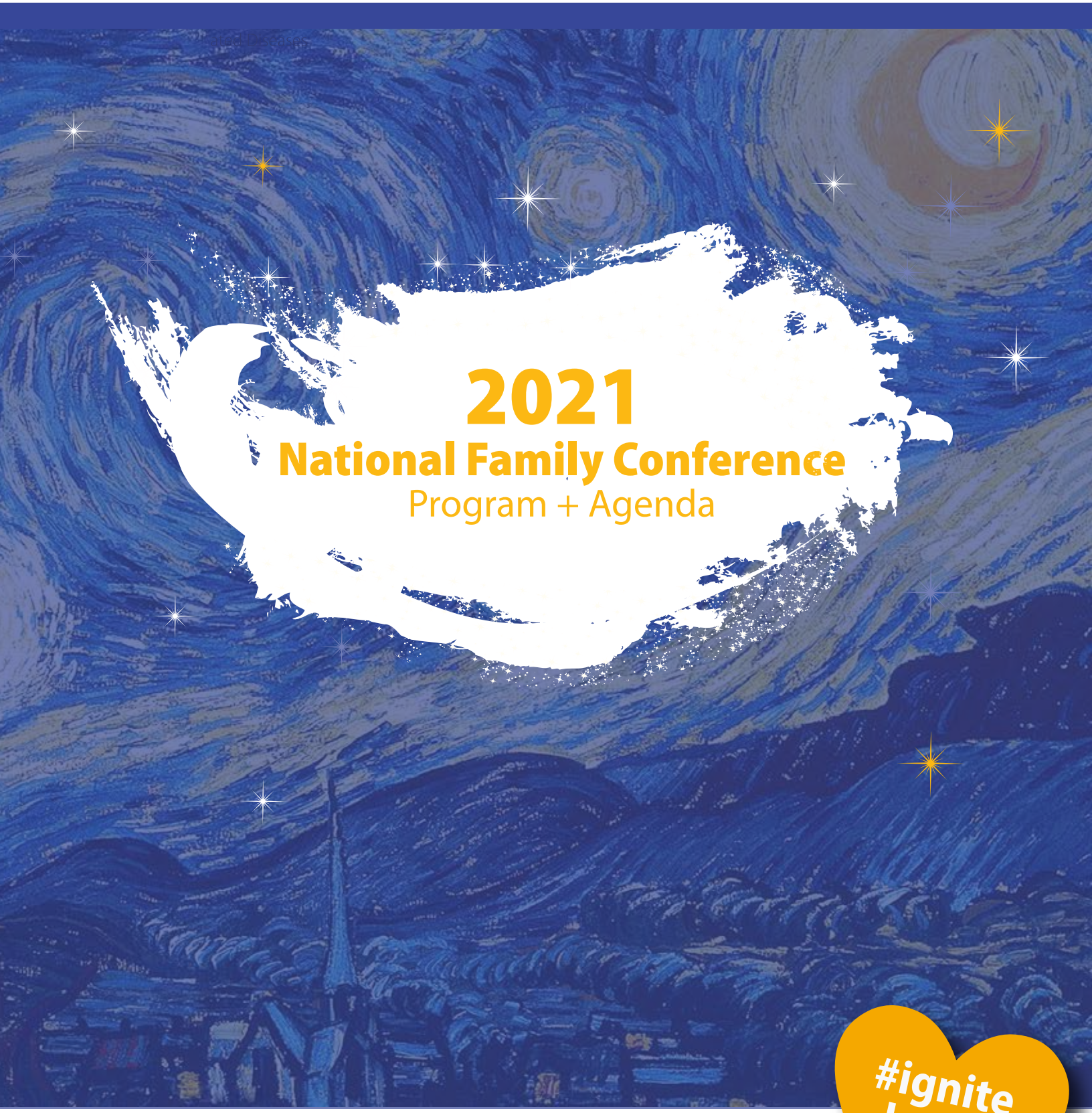
Canadian MPS Society
for Mucopolysaccharide & Related Diseases



2021
National Family Conference
Program + Agenda

#ignite hope

Support for Families. Research for a Cure.

2021 National Family Conference

Canadian MPS Society
for Mucopolysaccharide & Related Diseases

Letter From The Executive Director

Dear Canadian MPS Society Members & Associates,

We are excited to bring to you our **2021 *Virtual* National Family Conference!** Founded in 1984, The Canadian MPS Society, is committed to providing support to individuals and families affected with MPS and Related Diseases.

Our bi-annual conferences give affected families an opportunity to learn about new research, treatment and care, and to share information and experiences with other families and individuals. Because MPS diseases are very rare, our conferences often represent the only opportunities families have to meet others whose family members share the same experiences.

We hope that delegates will enjoy the three days of knowledge translation and networking sessions and experience a feeling of connectedness to others who are facing similar challenges and a sense of hope for the future. We also hope that children and siblings in attendance will leave the conference with new friendships and a new understanding of other children in Canada who are dealing with similar circumstances. Undoubtedly, new collaborative possibilities will emerge between the Society and the various stakeholders in attendance, and we welcome the chance to work together toward a brighter future for those Canadians affected with and by MPS and Related Diseases.

On behalf of the Board or Directors, staff and members, I would like to extend a very special thank you to our sponsors, our volunteers, all of the presenters, Bespoke, Orbitz, Erika Tibbe Design, Talbot Promotions, and to the incredible MPS Society Team Organizers: Alexandra Wyatt, Priya Ramakrishnan and Jocelyn Chee, and Angela Dai.

Please enjoy the conference and **we hope to see you in person in 2023**.

Kim Angel
Executive Director
Canadian MPS Society

don't miss out!

We have the opportunity to offer **Free tickets for the 2021 Gala** to affected family members. If taking part is at all a financial consideration, please don't hesitate to contact Kim Angel directly at kimangel@mpssociety.ca

We hope to see you at our Gala...

A RARE & Starry Night

October 2nd, 2021

2021 National Family Conference

Program Agenda : Wednesday September 15

Time	Presentation
3:00 PM – 3:10PM EST 12:00PM – 12:10PM PST	Opening Ceremonies & Introduction & House Keeping
3:10PM – 3:30PM EST 12:10 PM – 12:30PM PST	Keynote Speaker *Lorne Clarke, MD*
3:30 PM – 4:00 PM EST 12:30 PM – 1:00PM PST	InformRARE Team: Canadian MPS Registry Updates *Dr. Beth Potter, PhD* *Dr. Michal Inbar-Feigenberg, MD* *Dr. John Mitchell, MD*
4:00 PM – 5:00PM EST 1:00 PM– 2:00 PM PST	Canadian MPS Newborn Screening Updates *Patient perspective: Cristina Chiapetta* *Multiplex screening:Dr Christiane Auray-Blais, PhD* *MPS I-H Newborn Screening Updates: NSO*
5:00PM – 5:30 PM EST 2:00 PM– 2:30 PM PST	Q&A *InformRARE MPS Registry & Newborn Screening*
5:30 PM – 6:00PM EST 2:30 PM – 3:00 PM PST	Break
6:00PM – 6:20PM EST 3:00 PM – 3:20 PM PST	Canadian Organization for Rare Disorders: Update on Rare Disease Drug Plan *Dr. Durhane Wong-Rieger, PhD*
6:20 PM – 6:40 PM EST 3:20 PM – 3:40 PM PST	Canadian COVID-19 Update & Into the Future *Dr. Scott Halperin, MD*
6:40 PM – 6:55 PM EST 3:40 PM – 3:55PM PST	Q&A *Rare Disease Drug Plan & COVID-19 Updates*
6:55 – 7:00 PM EST 3:55 – 4:00 PM PST	Closing Remarks

A special *thank you* to our proud Gold Event Sponsors:

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2021 National Family Conference

Canadian MPS Society
for Mucopolysaccharide & Related Diseases

Message From The Board Chair

Dear Canadian MPS Society Members & Associates,

I am happy to welcome all of our members to this **virtual National Family Conference during the 37th Anniversary of the formation of the Canadian MPS Society.** I don't think I speak only for myself when I say it is one of the most important events we have the pleasure to host.

Despite the challenges that we have all faced during the pandemic, it is so important for us to come together, as a community that supports and uplifts each other.

This event is made possible by the collective work of many. Thank you to the presenters who have taken the time to develop their presentations and attend the Q&A sessions and who dedicate themselves to research, advocacy and care.

Thank you to our employees and volunteers without whom these events would not be possible. I can say without a shadow of a doubt that their dedication, compassion and care are what makes these events possible. The extent of their involvement goes well beyond the role of mere employees and is more that of dear friends. Lastly, thank you to the Board of Directors for their contributions to the event and continuous guidance and stewardship of the **Canadian MPS Society.**

Melissa Bilodeau

Melissa Bilodeau
Board Chair
Canadian MSP Society

A RARE Starry Night

October 2nd, 2021

Click HERE to register for the Gala. **Click HERE to check out the online auction.**

2021 National Family Conference

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Speakers & Biographies

Dr Lorne Clarke, MD

Dr. Lorne Clarke is a professor of medical genetics at the University of British Columbia, Canada and is a clinical and biochemical geneticist in the Provincial Medical Genetics Program for the Province of British Columbia. He served as medical director of the provincial program for 5 years and is currently the acting head of the genetics research cluster at the Child and Family Health Research Institute at UBC. He received his initial training in biochemistry and medicine at McGill University and is certified in paediatrics, clinical genetics and biochemical genetics. He has been active in fundamental research for over 20 years studying the basic pathophysiology of lysosomal storage disease with particular interest in biomarkers of disease and murine models.

Beth Potter, PhD

Beth Potter has a PhD in Epidemiology from the University of Western Ontario. She is currently an Associate Professor of Epidemiology and Public Health and the University Research Chair in Health Services for Children with Rare Diseases at the University of Ottawa. She is also an Affiliate Investigator at the Children's Hospital of Eastern Ontario. Her research focuses on developing evidence to improve health care for children with rare genetic diseases, particularly inherited metabolic diseases, and to inform newborn screening programs. Dr. Potter is Principal Investigator for the Canadian Inherited Metabolic Diseases Research Network (www.cimdrn.ca), and INFORM RARE (www.informrare.ca

Michal Inbar-Feigenberg, MD

Dr. Michal Inbar-Feigenberg is a Metabolic Geneticist in the Division of Clinical and Metabolic Genetics at the Hospital for Sick Children. She completed a General Pediatric Residency Program at the Hadassah Hospital, Hebrew University, Israel. Thereafter, she completed CCMG Clinical Biochemical Genetics Fellowship training at the University of Toronto. Dr. Inbar-Feigenberg's research is focused on lysosomal diseases. She is interested in the ability to translate our growing understanding of cellular mechanisms to utilize drugs for the benefit of patients.

Dr John Mitchell, MD

Dr. John Mitchell is a pediatric endocrinologist and biochemical geneticist at the Montreal Children's Hospital. He follows over 50 patients with lysosomal storage diseases. He has been involved in research in biomarkers, clinical outcome and cutting-edge therapeutics with the mucopolysaccharidoses for the past 15 years. He has participated in national and international guideline development for the treatment of individuals with these disorders. He has recently opened the first Canadian site for gene therapy for Hunter syndrome.

2021 National Family Conference

Program Agenda : Thursday, September 16

Time	Presentation
Room 1 12:00PM – 2:00PM EST 9:00AM – 11:00 AM PST	General Parent Networking Room
Room 2 12:00PM – 2:00PM EST 9:00AM – 11:00 AM PST	MPS Youth Networking Room (Affected youth & siblings)
Room 3 12:00PM – 2:00PM EST 9:00AM – 11:00 AM PST	MPS with Neurocognitive Manifestations: Networking Room
Room 4 12:00PM – 2:00PM EST 9:00AM – 11:00 AM PST	MPS without Neurocognitive Manifestations: Networking Room

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Speakers & Biographies

Christina Chiappetta

Cristina Chiappetta is a member of the Canadian MPS Society and mother to Gianna, the first child diagnosed with MPS I-H through newborn screening panels in Canada. Cristina is an advocate for newborn screening for MPS, as she believes every child should have the same opportunity Gianna did. Cristina has a passion for helping people find their dream homes and has been in the real estate world for several years.

You can follow their MPS journey on Instagram @giannas.stripes

Christiane Auray-Blais, PhD

Christiane Auray-Blais is the Director of the Neonatal Urine Screening Program for hereditary metabolic disorders in Sherbrooke, QC. More than 3 550 000 newborn babies were screened in the Province of Quebec for disorders of amino acids and organic acids. She holds a Ph.D. in radiobiology from the Faculty of Medicine and Health Sciences (FMHS) at the Université de Sherbrooke and postdoctoral studies from Duke University Medical Center in North Carolina, US. She has a master's degree in Health Law from the Faculty of Law at the Université de Sherbrooke and postdoctoral studies from Duke University Medical Center in North Carolina, US. She has a master's degree in Health Law from the Faculty of Law at the Université de Sherbrooke and a bachelor's degree in biochemistry. She is the author of more than 300 publications, book chapters, abstracts and articles.

She is a full professor in the Medical Genetics Division in the Department of Pediatrics at the FMHS and a researcher at the Clinical Research Centre in Sherbrooke, and in the Mother-Child Axis. She is the Scientific Director for the Waters-CHUS Expertise Centre in Clinical Mass Spectrometry and the Director at the Waters Center of Innovation in Sherbrooke. She is the principal investigator and co-investigator in numerous research grants. She has received awards for her involvement and expertise in preventive genetic medicine.

Durhane Wong-Rieger, PhD

DURHANE WONG-RIEGER, PHD is President & CEO of the Canadian Organization for Rare Disorders, Chair of the Consumer Advocare Network, President & CEO of the Institute for Optimizing Health Outcomes and Chair of Canadian Heart Patient Alliance.

Internationally, she is Chair of Rare Disease International, Chair of Asia Pacific Rare Disease International, Treasurer of United Nations Nongovernmental Organization for Rare Diseases. Chair of Patient Advocates Constituency Committee of the International Rare Disease Research Consortium, Patient Advisor to the APEC Rare Disease Network, member of the Editorial Board of The Patient- Patient Centred Outcomes Research, member of the Global Commission to End the Diagnostic Odyssey for Rare Diseases and member of Health Technology Assessment International Patient /Citizen Involvement Interest Group.

Dr. Wong-Rieger has served on numerous health policy advisory committees and panels and is a member of Ontario's Rare Disease Implementation Working Group and member of Genome Canada Steering Committee for the Rare Disease Precision Health Initiative. She is a certified Health Coach.

Durhane has a PhD in psychology from McGill University and was professor at the University of Windsor, Canada. She is a trainer and frequent lecturer and author of three books and many articles.

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Speakers & Biographies

Scott Halperin, MD

Dr. Scott Halperin is a Professor of Pediatrics and Microbiology and Immunology at Dalhousie University in Halifax, Nova Scotia. As Director of the Canadian Center for Vaccinology and Nominated Principal Investigator of the Canadian Immunization Research Network, he has played a foundational role in the establishment of these and other Canadian collaborative research networks undertaking evaluative vaccine research that informs public health policy and practice. Dr. Halperin's area of expertise is pertussis, and his research focuses on the diagnosis, treatment, and prevention of pertussis and other vaccine-preventable diseases. He currently serves on the national COVID-19 Immunity Task Force.

Liss Cairns

Liss Cairns (they/them) is the current Project Coordinator with Plan Institute, a national non-profit organization and social enterprise that supports people with disabilities through advocacy, education, and community partnerships. Liss graduated from Simon Fraser University in June 2019 with their Bachelor of Arts Degree in Criminology and Psychology.

Julie Larivière

Julie Larivière is a member of the Canadian MPS Society board of directors, a mom and advocate for individuals of all abilities. With the Society she is mostly known as the stepmom to (bonus) daughter Arielle who has MPS1-H. Julie has been working in the social services field for upwards of 10 years and has spent extensive time navigating the complex world of disability services in both her professional and personal life, particularly in the province of Ontario.

Robin Ibbotson-Rickard, RN

Robin has been with Innomar Strategies for over 12 years with leadership roles in both the Nursing & Clinic department and in her current role as Stakeholder Relations Manager-Ontario. In her role Robin works with physicians, healthcare providers, hospitals and patient groups in a variety of therapeutic areas to bring forward opportunities to enhance Innomar's services.

Robin has been a Registered Nurse for 35 years and has experience in all sectors of health care spending most of her nursing career in acute care within the critical care areas. Robin recently returned to Long-Term Care to support a local home during COVID 19.

2021 National Family Conference

Program Agenda : Friday, September 17

Time	Presentation
3:00 PM – 3:05 PM EST 12:00 PM – 12:05 PM PST	Welcoming & Housekeeping Message *Canadian MPS Society Staff*
3:05 PM – 3:25 PM EST 12:05 PM – 12:25 PM PST	PLAN Institute: Financial Planning with the Registered Disability Savings Plan (RDSP) *Liss Cairns*
3:35 PM – 3:45 PM EST 12:25 – 12:45 PM PST	Navigating and accessing disability services *Julie Larivière, MPS parent*
3:45 PM EST – 4:00 PM EST 12:45 PM – 1:00PM PST	Financial and Disability Services Q&A
4:00 PM EST – 4:30 PM EST 1:00PM – 1:30 PM PST	Break
4:30 PM – 4:50 PM EST 1:30 PM – 1:50 PM PST	Mobility & Musculoskeletal Management *Dr. Reggie Hamdy, MD*
4:50 PM – 5:10 PM EST 1:50 PM – 2:10 PM PST	Innomar Services: Home Infusion Management *Robin Ibbotson-Rickard, RN* *Toni Salvati*
5:10 PM – 5:30 PM EST 2:10 PM – 2:30 PM PST	Psychological and Behavioural Management *Dr. Eva Mamak, PhD*
5:30 PM – 5:50 PM EST	

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Speakers & Biographies

Toni Salvati, RN

Toni Salvati is a Registered Nurse, graduated from University of Toronto and Sheridan College of Nursing in 1990. She has worked in inpatient psychiatry, labour and delivery and currently as a field nurse at Innomar Strategies since 2014. Her passion is working the front line and providing patient care. Toni has been a MPS program nurse champion at Innomar since 2015, providing training to new nurses about the conditions and treatments for MPS patients.

Eva Mamak, PhD

Dr. Eva Mamak is a board-certified clinical neuropsychologist at the Hospital for Sick Children in Toronto, Ontario. Her clinical work is focused on evidence-based assessment of infants, toddlers, children, and adolescents with rare disease, genetic conditions, and medication-refractory epilepsy.

Dr. Mamak's research focuses on neurocognitive outcomes in rare disease and neurological conditions, with a focus on multi-disciplinary, multi-centre studies. Clinical monitoring of functional outcomes following novel treatment is also a focus of her work. Dr. Mamak is involved in clinical training at the pre- and post-doctoral level.

Reggie Hamdy, MD

I am a paediatric orthopaedic surgeon. I completed my medical degree at the University of Alexandria and my post-graduate training and residency in orthopaedics at the University of Ottawa, and my fellowship training in Paediatric Orthopedics at the Hospital for Sick Children, Toronto, for one year as well as in the Paediatric Orthopaedic Division, Brown University in Providence, Rhode Island for 2 years, in addition, I completed a clinical and research fellowship at the University of Montreal.

My main clinical interests include the management of children with complex conditions such as Osteogenesis Imperfecta (OI) skeletal dysplasias, neuromuscular conditions specifically arthrogryposis and children and adolescents with limb deformities (angular and rotational)

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2021 National Family Conference

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