

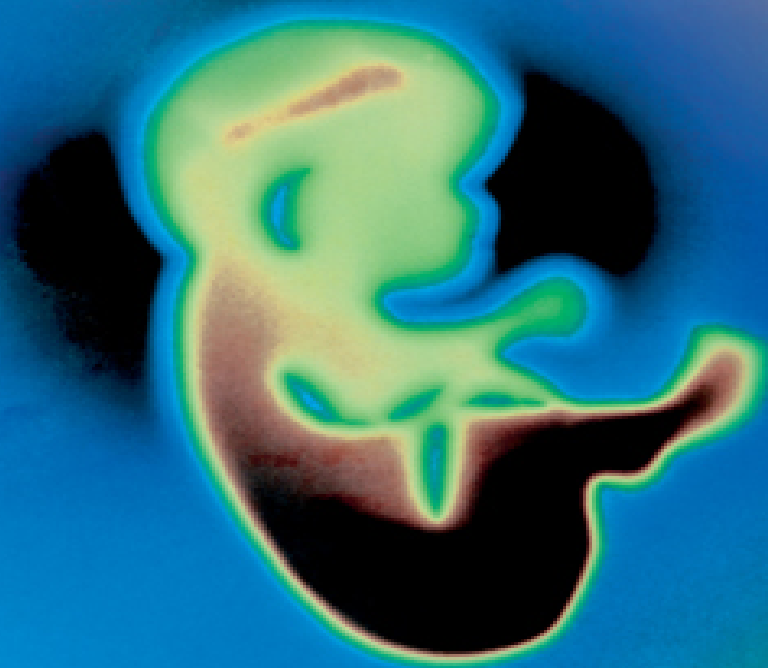


Health Care and Disease Management

# Fetal Alcohol Spectrum Disorder

Management and Policy Perspectives of FASD

Edited by Edward P. Riley, Sterling Clarren,  
Joanne Weinberg, and Egon Jonsson



**IHE** INSTITUTE OF  
HEALTH ECONOMICS  
ALBERTA CANADA

 **WILEY-  
BLACKWELL**



Health Care and Disease Management

# Fetal Alcohol Spectrum Disorder

Management and Policy Perspectives of FASD

Edited by Edward P. Riley, Sterling Clarren,  
Joanne Weinberg, and Egon Jonsson

**IHE** INSTITUTE OF  
HEALTH ECONOMICS  
AND POLICY STUDIES

 **WILEY-  
BLACKWELL**

# Contents

**Cover**

**Half Title page**

**Title page**

**Copyright page**

**Preface**

**List of Contributors**

**Chapter 1: Prenatal Alcohol Exposure, FAS, and FASD: An Introduction**

**1.1 Introduction**

**1.2 History**

**1.3 Diagnosing the Effects of Prenatal Alcohol Exposure**

**1.4 Risk factors influencing FAS and FASD Conditions**

**1.5 Prevalence and Impact of FAS and FASD**

**1.6 Prevention**

**1.7 Interventions**

**Acknowledgments**

**References**

# **Part One: Incidence, Prevalence, and Economic Aspects of FASD**

## **Chapter 2: Researching the Prevalence and Characteristics of FASD in International Settings**

### **2.1 Introduction**

### **2.2 Maternal Risk Factors and FASD**

### **2.3 Determining the Prevalence of FASD: How the Methods Have Influenced the Rates**

### **2.4 The Prevalence of FASD from In-School Studies**

### **2.5 Summary Rates of FASD and Their Meaning**

### **References**

## **Chapter 3: Frequency of FASD in Canada, and What This Means for Prevention Efforts**

### **3.1 Introduction**

### **3.2 Challenges to Obtaining Accurate Incidence and Prevalence Rates**

### **3.3 Incidence of FASD**

### **3.4 Prevalence of FASD**

### **3.5 Rate of Exposure to Risk**

### **3.6 Gaps in the Data**

**3.7 Policy Considerations**

**3.8 Conclusions**

**Acknowledgments**

**References**

## **Chapter 4: Costs of FASD**

**4.1 Introduction**

**4.2 Methods**

**4.3 Results**

**4.4 Discussion**

**4.5 Conclusion**

**4.6 Appendices to Chapter 4**

**4.6.2 Appendix 2: Summary of Included Studies**

**References**

## **Part Two: Causes and Diagnosing of FASD**

### **Chapter 5: Direct and Indirect Mechanisms of Alcohol Teratogenesis: Implications for Understanding Alterations in Brain and Behavior in FASD**

**5.1 Introduction**

**5.2 Fetal Programming: Programming of the HPA Axis by PAE**

**5.3 Altered Epigenetic Regulation of Gene Expression: A Possible Mechanism**

**Underlying Fetal Programming of the HPA Axis and Altered Neuroendocrine-Immune Interactions**

**5.4 Prenatal Alcohol Exposure: Early Experience, Stress Responsiveness, and Vulnerability to Depression**

**5.5 FASD and Substance Abuse**

**5.6 Summary and Policy Considerations**

**Acknowledgments**

**Glossary**

**Abbreviations**

**References**

**Chapter 6: Genetic Factors Contributing to FASD**

**6.1 Introduction**

**6.2 The Evidence**

**6.3 Genetic Factors in Alcohol Metabolism**

**6.4 Some Genetic Factors**

**6.5 Epigenetics, the Environment and Nutrition**

**6.6 Conclusions, and Some Policy Recommendations**

**6.7 Glossary**

**References**

**Chapter 7: Diagnosis of FASD: An Overview**

**7.1 History of Diagnosing FASD**  
**7.2 How Does Prenatal Alcohol Exposure Cause Damage?**  
**7.3 Screening for FASD**  
**7.4 The Diagnostic Process**  
**7.5 FASD Across the Lifespan**  
**7.6 Implications of a Diagnosis of FASD**  
**7.7 Conclusion and Future Directions**  
**7.8 Policy Considerations**  
**References**

## **Part Three: Prevention Policies and Programs**

### **Chapter 8: FASD: A Preconception Prevention Initiative**

**8.1 Introduction**  
**8.2 Prevention Strategies**  
**8.3 Research Relationships**  
**8.4 The CIHR Guidelines for Research Involving Aboriginal People**  
**8.5 Summary**  
**Acknowledgments**  
**References**

### **Chapter 9: Bringing a Women's Health Perspective to FASD Prevention**

**9.1 Introduction**

**9.2 Applying Gender-Based Analysis to FASD Prevention**

**9.3 Developing a Framework for Women-Centered Prevention Practice**

**9.4 Evidencing the Framework**

**9.5 Conclusions**

**References**

## **Chapter 10: Next Steps in FASD Primary Prevention**

**10.1 Introduction**

**10.2 Current State of FASD Primary Prevention in North-Western Canada**

**10.3 Campaign Evaluation: What Is It and Why It Is Important**

**10.4 Incorporating Social Marketing Strategies**

**10.5 Creating Behavioral Change: Protection Motivation Theory**

**10.6 Future Considerations for Health Promoters and Policy Makers**

**References**

## **Chapter 11: Preventing FASD: The Parent-Child Assistance Program (PCAP) Intervention with High-Risk Mothers**

**11.1 Introduction**



**11.2 FASD Prevention**

**11.3 Background**

**11.4 The PCAP Intervention**

**11.5 PCAP: A Two-Pronged Intervention**

**11.6 Preventing Alcohol- and/or Drug-Exposed Births**

**11.7 PCAP Outcomes**

**11.8 PCAP Cost Effectiveness**

**11.9 PCAP Intervention with Women who Themselves Have FASD**

**11.10 Policy Recommendations: Collaborative Approaches for Preventing Alcohol-Exposed Pregnancies**

**References**

## **Chapter 12: FASD in the Perspective of Primary Healthcare**

**12.1 Primary Care Approaches to FASD**

**12.2 Barriers to Screening**

**12.3 Impact of Healthcare Reform**

**Reference**

## **Part Four: FASD and the Legal System**

### **Chapter 13: The Manitoba FASD Youth Justice Program: Addressing Criminal Justice Issues**

**13.1 Introduction**

**13.2 The Legislative Context**

**13.3 The Information Gap**

**13.4 The Manitoba FASD Youth Justice Program**

**13.5 Screening**

**13.6 The Preassessment Period**

**13.7 Medical Assessment**

**13.8 The Doctor's Report and Its Use**

**13.9 Sentencing Conferences**

**13.10 The Sentencing Process**

**13.11 The Statistical Outcomes**

**13.12 One-Day Snap-Shot of Age of Majority Youth (28 February 2010)**

**13.13 Other Initiatives**

**13.14 Strengths and Challenges**  
**References**

## **Chapter 14: Understanding FASD: Disability and Social Supports for Adult Offenders**

**14.1 Fetal Alcohol Spectrum Disorder (FASD) is a Disability**

**14.2 Correctional Environment in Canada for Adults with FASD**

**14.3 Interventions and Social Supports for Adults with FASD after Release**

**14.4 Policy Considerations for Adults with FASD**

## **References**

### **Chapter 15: Policy Development in FASD for Individuals and Families Across the Lifespan**

#### **15.1 Introduction**

#### **15.2 Birth**

#### **15.3 Childhood**

#### **15.4 Adolescence/Teenage Years**

#### **15.5 Adulthood**

#### **15.6 A Disability Paradigm for FASD**

#### **15.7 Cultural Fairness**

#### **15.8 Life Trajectory Policy Model**

#### **15.9 Conclusions**

#### **References**

### **Chapter 16: The Impact of FASD: Children with FASD Involved with the Manitoba Child Welfare System**

#### **16.1 Introduction**

#### **16.2 Study One: Children in Care with Disabilities**

#### **16.3 Study Two: The Trajectory of Care for Children with FASD**

#### **16.4 Study Three: Youth with FASD Leaving Care**

#### **16.5 Study Four: The Cost of Child Welfare Care for Children with FASD**

**16.6 Study Five: Economic Impact of FASD  
for Children in Care**

**16.7 Conclusions**

**References**

## **Chapter 17: British Columbia's Key Worker and Parent Support Program: Evaluation Highlights and Implications for Practice and Policy**

**17.1 Introduction**

**17.2 Background**

**17.3 Program Model and Components**

**17.4 Literature**

**17.5 Evaluation Methods**

**17.6 Formative Evaluation Findings**

**17.7 Summative Evaluation Findings**

**17.8 Discussion**

**17.9 Policy Considerations**

**17.10 Conclusions**

**References**

## **Chapter 18: FASD and Education Policy: Issues and Directions**

**18.1 Introduction**

**18.2 Where Do Students with FASD Fit Into  
the Education System?**

**18.3 Students with FASD within Special  
Education Systems**

**18.4 Education Professionals and FASD**

**18.5 Inter-Agency and Community Supports  
for Students with FASD**

**18.6 Policy Indications**

**18.7 Conclusions**

**References**

## **Chapter 19: Shifting Responsibility from the Individual to the Community**

**19.1 Introduction**

**19.2 Why Do We Need to Make a Shift?**

**19.3 Examples of Individual's Situations**

**19.4 One Model of Community of Care**

**19.5 History**

**19.6 Future**

**19.7 Policy Considerations**

**19.8 Conclusions**

**Acknowledgments**

**References**

## **Chapter 20: A Social Work Perspective on Policies to Prevent Alcohol Consumption during Pregnancy**

**Appendix to Chapter 20**

**References**

## **Chapter 21: A Cross-Ministry Approach to FASD Across the**

## **Lifespan in Alberta**

**21.1 Introduction**

**21.2 The Impact of FASD**

**21.3 Overview of Strategies**

**21.4 FASD Service Network Program**

**21.5 Ministry Initiatives Based on the Strategic Plan**

**References**

## **Chapter 22: Critical Considerations for Intervention Planning for Children with FASD**

**22.1 Introduction**

**22.2 The Development of a Rational Service System for At-Risk Children**

**22.3 Factors Supporting the Development of Separate Specialized Services for Subgroups of At-Risk Children**

**22.4 Should Separate Specialized Services Be Developed for Children with FASD?**

**22.5 Policy Considerations: Strengthening the Service System for a Broader Range of Children At-Risk**

**Acknowledgments**

**References**

## **Part Five: Research Needed on FASD**

## **Chapter 23: FASD Research in Primary, Secondary, and Tertiary Prevention: Building the Next Generation of Health and Social Policy Responses**

### **23.1 Introduction**

### **23.2 Mapping Prevention: What Research is Needed Now, and Why?**

### **23.3 Conclusions: Drawing a Road-Map for Integrated, Supportive, and Effective Care** **References**

## **Chapter 24: Focusing Research Efforts: What Further Research into FASD is Needed?**

### **24.1 Introduction**

### **24.2 FASD and Heterogeneity: An Encouraging Outcome**

### **24.3 Models: Moving Beyond Description**

### **24.4 Applying Neuroscience: Beyond the Mother?**

### **24.5 Summary** **References**

## **Part Six: Personal Views from People Living with FASD**

### **Chapter 25: Living with FASD**

## **Chapter 26: Charlene's Journey**

### **Appendix: FASD Consensus Statement of the Jury**

**Acknowledgments**

**Process**

**Conference Questions**

**Introduction**

**Question 1**

**Question 2**

**Question 3**

**Question 4**

**Question 5**

**Question 6**

**Conclusion**

**Jury Members**

**Conference Speakers and Topics**

**Planning Committee**

**Scientific Committee**

**Communications Committee**

**Disclosure Statement**

**Institute of Health Economics**

**IHE Board of Directors**

**FASD Research and Resources**

**Index**



***Edited by  
Edward P. Riley,  
Sterling Clarren,  
Joanne Weinberg,  
and Egon Jonsson***

# Fetal Alcohol Spectrum Disorder

***Titles of the series***  
***“Health Care and Disease***  
***Management”***

Martin, W., Suchowersky, O.,  
Kovacs Burns, K., Jonsson, E. (eds.)

**Parkinson Disease**  
**A Health Policy Perspective**

2010

ISBN: 978-3-527-32779-9

Rapoport, J., Jacobs, P., Jonsson, E. (eds.)

**Cost Containment and**  
**Efficiency in National**  
**Health Systems**  
**A Global Comparison**

2009

ISBN: 978-3-527-32110-0

***Forthcoming***

Clarren, S., Salmon, A., Jonsson, E. (Eds.)

**Prevention of Fetal Alcohol**  
**Spectrum Disorder FASD:**  
**Who Is Responsible?**

2011

978-3-527-32997-7

Lu, M., Jonsson, E. (eds.)

**Financing Health Care**  
**New Ideas for a Changing Society**

2008

ISBN: 978-3-527-32027-1

Rashiq, S., Schopfl ocher, D.,

Taenzer, P., Jonsson, E. (eds.)

**Chronic Pain**

**A Health Policy Perspective**

2008

ISBN: 978-3-527-32382-1

***Related Titles***

Miller, N.S., Gold, M.S. (Eds.)

Addictive Disorders in Medical  
Populations

2010

ISBN: 978-0-470-74033-0

Mitcheson, L., Maslin, J., Meynen, T.,  
Morrison, T., Hill, R., Wanigaratne, S.,  
Padesky, C.A. (Foreword by)

**Applied Cognitive and  
Behavioural Approaches to  
the Treatment of Addiction:  
A Practical Treatment Guide**

2010

ISBN: 978-0-470-51062-9

*Edited by Edward P. Riley, Sterling Clarren,  
Joanne Weinberg, and Egon Jonsson*

## **Fetal Alcohol Spectrum Disorder**

Management and Policy Perspectives of FASD

 **WILEY-BLACKWELL**

## **The Editors**

### **Prof. Dr. Edward P. Riley**

San Diego State University  
Center for Behavioral Teratology  
6363, Alvarado Ct. #209  
San Diego, CA 92120  
USA

### **Prof. Dr. Sterling Clarren**

University of British Columbia  
Faculty of Medicine — Pediatrics  
L408 — Oak Street 4480  
Vancouver, BC V6H 3V4  
Canada

### **Dr. Joanne Weinberg**

University of British Columbia  
Department of Cellular &  
Physiological Sciences  
Health Sciences Mall 2350  
Vancouver, BC V6T 1Z3  
Canada

### **Prof. Dr. Egon Jonsson**

University of Alberta  
University of Calgary  
Department of Public  
Health Science  
Institute of Health Economics  
10405 Jasper Ave  
Edmonton, Alberta T5J 3N4  
Canada

## **Series Editor**

### **Prof. Dr. Egon Jonsson**

University of Alberta  
University of Calgary

Department of Public  
Health Science  
Institute of Health Economics  
10405 Jasper Ave  
Edmonton, Alberta T5J 3N4  
Canada

**Cover**

Photo: PhotoDisc/Getty

**Limit of Liability/Disclaimer of Warranty:** While the publisher and author have used their best efforts in preparing this book, they make no representations or warranties with respect to the accuracy or completeness of the contents of this book and specifically disclaim any implied warranties of merchantability or fitness for a particular purpose. No warranty can be created or extended by sales representatives or written sales materials. The Advice and strategies contained herein may not be suitable for your situation. You should consult with a professional where appropriate. Neither the publisher nor authors shall be liable for any loss of profit or any other commercial damages, including but not limited to special, incidental, consequential, or other damages.

**Library of Congress Card No.:** applied for

**British Library Cataloguing-in-Publication Data** A catalogue record for this book is available from the British Library.

**Bibliographic information published by the Deutsche Nationalbibliothek**

The Deutsche Nationalbibliothek lists this publication in the Deutsche Nationalbibliografie; detailed bibliographic data are available on the Internet at <<http://dnb.d-nb.de>>.

© 2011 Wiley-VCH Verlag & Co. KGaA, Boschstr. 12, 69469  
Weinheim, Germany

**Wiley-Blackwell** is an imprint of John Wiley & Sons, formed by the merger of Wiley's global Scientific, Technical, and Medical business with Blackwell Publishing.

All rights reserved (including those of translation into other languages). No part of this book may be reproduced in any form — by photoprinting, microfilm, or any other means — nor transmitted or translated into a machine language without written permission from the publishers. Registered names, trademarks, etc. used in this book, even when not specifically marked as such, are not to be considered unprotected by law.

**Cover Design** Adam-Design, Weinheim

**ISBN:** 978-3-527-32839-0

**ISSN:** 1864-9947

# ***Preface***

In October 2009, the Institute of Health Economics (IHE) staged a consensus development conference to address key questions about the prevention, diagnosis, and treatment of Fetal Alcohol Spectrum Disorder (FASD). Experts in the field presented scientific evidence to a “jury” about prevention and the social determinants that may induce drinking during pregnancy, the importance of diagnosis, the impact of FASD across a person’s lifespan, and the community supports needed for those living with FASD, as well as their families. After two days of hearings, the jury developed a statement which answered eight relevant and common questions about FASD, including suggested policy changes for enhanced prevention, and for improving the lives of people with FASD and their families. That statement is available in the Appendix of this book.

During the planning of that conference, IHE invited the experts – who included researchers, clinicians, economists, epidemiologists, social workers, and judicial workers – to expand on their speeches and write chapters for a book that would aim at a worldwide health policy-making audience. An overwhelming majority of the speakers were interested, and this book is the result of their hard work.

In addition to policy makers, this book is for anyone interested in FASD, including those with the condition, family members and other caregivers, researchers, clinicians and others in healthcare and social services, and the justice sector. The chapters describe the impact of FASD on the individual, their families and society, and the many complex issues involved in the condition’s prevention, diagnosis, and treatment. The book ends with personal accounts of life with FASD, written by Myles Himmelreich and Charlene Organ, that not only powerfully illustrate the



challenges created by having FASD, but also serve as a reminder that FASD does not – and should never – define a person.

We would like to acknowledge the Government of Alberta FASD Cross-Ministry Committee, Canada Northwest FASD Partnership, Health Canada and the Public Health Agency of Canada for their financial support of the consensus development conference and the production of material to this book. We would also like to thank Minister Janis Tarchuk, who was Minister of Children and Youth Services at the time of the conference and Deputy Minister, Fay Orr, for their strong support. Special recognition should be given to Ms Denise Milne, who represented the Cross-Ministry Committee and assisted greatly in all aspects of the conference preparations. We are very grateful to the Honorable Anne McLellan for serving as Chair of the Jury for the conference, to Dr Gail Andrew, who acted as the Scientific Chair, and Ms Nancy Reynolds who acted as moderator. Special mention should be made to the Honorable Iris Evans, Minister of International and Intergovernmental Relations for Alberta, who has been a tireless supporter of initiatives to improve the lives of those affected by FASD. We would also like to give special thanks to Gail Littlejohn for her support in the editing process of this publication.

On behalf of the Institute of Health Economics (IHE)  
([www.ihe.ca](http://www.ihe.ca))

*Egon Jonsson*

*John Sproule*

*Liz Dennett*

# ***List of Contributors***

## ***Noreen Agrey***

Saskatchewan Prevention Institute  
1319 Colony Street  
Saskatoon, Saskatchewan  
Canada S7N 2Z1

## ***Gail Andrew***

Alberta Health Services  
Glenrose Rehabilitation Hospital  
10230 111 Ave  
Edmonton, Alberta  
Canada AB T5G 0B7

## ***Dorothy Badry***

University of Calgary  
Faculty of Social Work  
2500 University Drive NW  
Calgary, Alberta  
Canada T2N 1N4

## ***Patricia G. Bailey***

University of Alberta  
Occupational Performance  
Analysis Unit  
1 - 78 Corbett Hall  
Edmonton, Alberta  
Canada T6G 2G4

## ***Lola Baydala***

University of Alberta  
Department of Pediatrics

Misericordia Child Health Clinic  
16930 - 87 Avenue  
Edmonton, Alberta  
Canada T5R 4H5

***June Bergman***

University of Calgary  
Department of Family Medicine  
Faculty of Medicine and Dentistry  
#1707, 1632 - 14th Avenue NW  
Calgary, Alberta  
Canada T2N 1M7

***Mary Diana (Vandenbrink) Berube***

Alberta Children and Youth Services  
Ministry Support Services  
12th Floor, Sterling Place,  
9940 - 106 Street  
Edmonton, Alberta  
Canada T5K 2N2

***Yagesh Bhambhani***

University of Alberta  
Occupational Performance Analysis  
Unit  
1 - 78 Corbett Hall  
Edmonton, Alberta  
Canada T6G 2G4

***Tamara Bodnar***

University of British Columbia  
Department of Cellular &  
Physiological Sciences  
2350 Health Sciences Mall  
Vancouver, BC

Canada BC V6T 1Z3

***Elizabeth Bredberg***

Bredberg Research and Consulting in  
Education (BRACE)  
2620 W 37th Ave  
Vancouver, British Columbia  
Canada V6N 2T4

***E. Sharon Brintnell***

University of Alberta  
Occupational Performance Analysis  
Unit  
1 - 78 Corbett Hall  
Edmonton, Alberta  
Canada T6G 2G4

***Marni Brownell***

University of Manitoba  
Manitoba Centre for Health Policy  
Community Health Sciences  
Faculty of Medicine  
408 - 727 McDermot Avenue  
Winnipeg, Manitoba  
Canada R3E 3P5

***Linda Burnside***

Manitoba Family Services and  
Housing  
Disability Programs and Employment  
& Income Assistance  
305 114 Garry Street  
Winnipeg, Manitoba  
Canada R3C 4V7

***Kelly Butts***

University of British Columbia  
UBC Institute of Mental Health  
Department of Psychiatry  
5950 University Blvd  
Vancouver, BC  
Canada BC V6T 1Z3

***Albert E. Chudley***

University of Manitoba  
Program in Genetics and Metabolism  
Professor, Department of Pediatrics  
and Child Health  
Department of Biochemistry and  
Medical Genetics  
FE 229 - 840 Sherbrook Street  
Winnipeg, Manitoba  
Canada MB R3A 1R9

***Magdalena Cismaru***

University of Regina  
Faculty of Business Administration  
3737 Wascana Parkway  
Regina, Saskatchewan  
Canada S4S 0A2

***Sterling Clarren***

Canada Northwest FASD Research  
Network  
L408 - 4480 Oak Street  
Vancouver, BC  
Canada V6H 3V4

***Wendy Comeau***

University of British Columbia

Department of Cellular &  
Physiological Sciences  
2350 Health Sciences Mall  
Vancouver, BC  
Canada BC V6T 1Z3

***Jennifer Coppens***

University of Alberta  
Doctor of Medicine Program  
Faculty of Medicine & Dentistry  
11025 Jasper Avenue #608  
Edmonton, Alberta  
Canada T5K 0K7

***Matthew Dahl***

University of Manitoba  
Manitoba Centre for Health Policy  
Community Health Sciences  
Faculty of Medicine  
408 - 727 McDermot Avenue  
Winnipeg, Manitoba  
Canada R3E 3P5

***Linda De Riviere***

University of Winnipeg  
515 Portage Avenue  
Winnipeg, Manitoba  
Canada R3B 2E9

***Liz Dennett***

Institute of Health Economics  
#1200, 10405 Jasper Ave  
Edmonton, Alberta  
Canada T5J 3N4