Author: Helen McFarland, 2014

License: Unless otherwise noted, this material is made available under the terms of the Creative Commons Attribution-NonCommercial 4.0 License: http://creativecommons.org/licenses/by-nc/4.0/

The University of Michigan Open.Michigan initiative has reviewed this material in accordance with U.S. Copyright Law and has tried to maximize your ability to use, share, and adapt it. Copyright holders of content included in this material should contact <u>open.michigan@umich.edu</u> with any questions, corrections, or clarification regarding the use of content.

For more information about how to attribute these materials visit: <u>http://open.umich.edu/education/about/terms-of-use</u>.

# **ICD Connection:**

Living with an implantable cardioverter defibrillator

A Collection of Stories from Women & Men

Helen McFarland, RN

Foreword by Frank Pelosi, Jr., MD

Cover Design by Marc R. Stephens Learning Design and Publishing, Medical School Information Services

Published by MPublishing, an imprint of Michigan Publishing University of Michigan Library

Copyright © 2015 The Regents of the University of Michigan

ISBN 978-1-60785-441-8

# DEDICATION

This book is dedicated to those who generously share their experiences to help others.

If I can stop one heart from breaking, I shall not live in vain; If I can ease one life the aching, Or cool one pain, Or help one fainting robin Unto his nest again, I shall not live in vain.

Emily Dickinson

# CONTENTS

Foreword
Frank Pelosi, Jr.,MD, FACC, FHRS
Preface
Helen McFarland, RN
T. 1
Introduction
Laura Horwood, NP
Frequently Asked Questions about ICDs
Laura Horwood, NP
Introduction to Women's Stories
Claire Duvernoy, MD
My Second Chance13
Jenna (ICD recipient)
Stay Gold
Wendy (ICD recipient)
The Other Girl
Jasmine (ICD recipient)
Heart of a World Traveler41
Lisa (ICD recipient)
An Uncertain Journey47
Ashlea (ICD recipient)
Obstacles to Opportunities
Michaela (ICD recipient)
Passion, Perseverance and the Gift of Challenge69
Renee (ICD recipient)

vi

A Quiet Courage77
Karen (Mother of ICD recipient)
Frequently Asked Questions about ICDs for Women
Coping with Life as a Woman with an ICD and Proposed Strategies for Success
Introduction to Men's Stories
My Journey
Ryan's Story – From Chaos to Growth
To 50and Beyond
The Heart
Count Your Blessings
My Miracle on Ice
Frequently Asked Questions about ICDs for Men
A Chapter for Men: Taking the Challenge of Seeking Help 163 Kevin Woodrow, MA, Sam Sears, PhD, John Cahill, MD

# vii

Resources	173
Pictures from Young ICD Connection Conference	175
About the Editor	

viii

# FOREWORD

I hope you enjoy the second edition of the *ICD Connection* series. The first edition was a tremendous success, and the stories that you will read in this edition will no doubt touch and inspire you.

*ICD Connection* tells the stories of people who have been touched by an unexpected and frightening diagnosis. Some of them experienced a near sudden-death experience, or have discovered that they are at risk, perhaps because of a diagnosis in a close relative. All of them have received an implantable cardioverter defibrillator, or ICD. You will also read stories about loved ones who live and love alongside those with ICDs as they move forward with their lives.

Some of you are reading this book because you are going through similar struggles. Some of you may have a loved one or a friend with an ICD. Some of you may be just curious about patients with ICDs. As you read these individuals' stories, please reflect on how the diagnosis of a life-threatening illness and the placement of an ICD has transformed their lives. The placement of an ICD forces one to see the world differently. At first, this difference is unsettling. Instead of directing life's circumstances, the circumstances and challenges now seem in control. Independence is now replaced with a dependence on others to provide treatments and advice. The future seems cloudy where hopes are now replaced with doubts.

But from this new reality, light graces the darkness. Family, friends, and caregivers rise to surround and support. With it, there comes a new appreciation for the daily blessings of life and the people and moments that touch them in small but meaningful ways. These people and these moments serve to guide, guard and protect in ways that are beyond mere coincidence

The title of this book, *ICD Connection*, is important. In our online, smartphone-savvy world, new applications emerge almost daily striving for new ways to connect with others, yet we still feel more isolated. That is because we were created for *connection* rather than isolation, for *interdependence* rather than independence. In many ways, social media can serve an important purpose, but we should

ix

not forget the healing power of a kind word, a touch, and a reassuring smile.

These stories are about *love*—a word we do not use enough. For many, it places us too far on an uncomfortable limb, but love is as much a choice as it is a feeling. When you read these stories, look for the choice of love. Some are obvious, some are subtle, but each one is a gift that connects us all.

As always, I want to thank these individuals for showing their love by sharing their stories with us. They may never know how much these stories will inspire and heal, but I know for many of you, they will light and guide you through your own personal journey.

Frank Pelosi, Jr., MD, FACC, FHRS Director, Cardiac Electrophysiology Fellowship University of Michigan Medical School

# PREFACE

In 2013, I was very fortunate to be a part of a collaborative effort to publish a collection of ICD recipients' and family members' personal stories of living life with an ICD. This book, *ICD Connection: Living with an Implantable Cardioverter Defibrillator. A Collection of Patient and Family Stories*, has received tremendous positive feedback from ICD recipients, their families and friends, and health care providers across the country. I have received e-mails and phone calls from patients who have newly implanted ICD's expressing gratitude for the book and the realization that they are not alone with the concerns, fears, depression, and/or anxiety they are experiencing. On the flip side, I have read the personal stories within the book and relayed to me that these stories helped them to come to a deeper understanding of what their patients are experiencing, and with this insight believe they will be a better resource for their patients.

Consequently, I thought it was worthwhile to look at another aspect of living with an ICD, specifically, the unique experiences of living with an ICD for women and also for men. Although much of the experience of having an ICD implanted is shared between the genders, there are unique experiences that only another woman can understand and vice versa for men. I am very thankful to the authors in this book who agreed to write about their personal journeys of living life with an ICD. Thank you to the women: Jenna, Wendy, Jasmine, Lisa, Ashlea, Michaela, Renee, and Karen. Thank you to the men: Brian, Peter, Ryan, Kevin, Rob, Alan, and George. Your stories will help so many who are new to ICD implantation and also those of us in the medical field who provide care for ICD recipients. Connecting with others who are experiencing similar situations can help us find encouragement and hope in our own situations. Thank you for your generosity.

I would like to thank Jasna Markovac, PhD and the Learning Design and Publishing team, Medical School Information Services at the University of Michigan for again providing expertise and guidance in bringing this project to fruition.

## xi

Lastly, I would like to thank the planning committee of the University of Michigan "Young ICD Connection Conference." The committee is made up of staff from the University of Michigan Congenital Heart Center and Frankel Cardiovascular Center. These committee members take great care each year to maintain a program that provides support and education for ICD recipients and their families and to do this in a festive manner.

Helen McFarland, RN University of Michigan Hospital August, 2014

xii