

The Renal Community Photo Initiative

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Introduction

These images have been created and shared by participants of the Renal Community Photo Initiative. Although this idea was conceived by Dr. Chris McIntyre and Dr. Joy James, it is very much a patient or participant-centered venture. Well over 1600 images have been created thanks to the enthusiasm and collaboration of all participants. Four participants in the study have also contributed their time as editors to this document: Anne, Elaine, Jared and Pam. Their images and the images of all our study participants provide “snapshots” that assist us in understanding the experiences of those living with chronic kidney disease.

We learn a great deal about perspective through this material, and we learn a great deal about the priorities of those who face challenges unfamiliar to others. These unique photographs—combined with open discussions, written logs and constructive feedback—challenged the research team to engage further with the participants, and we collaborated to develop a set of values by which their images could be circulated. The participants quickly identified valuable opportunities for sharing their experiences with others, those living with kidney disease and the community at large with the goal of raising awareness, emphasizing the importance of organ donation, and providing hope to those facing the unknown when initially diagnosed. The intimate discussions held with sub-study participants fostered a safe environment for sharing difficulties and opportunities. Participants discussed how to improve situations for people and families who may be facing similar health crises. One unanimous theme that recurred throughout these discussions was that of hope.

This study was approved by the Office of Human Research Ethics, Western University, Project ID: 108649.

We are grateful for participants’ courage, their generosity, and their stories.



12/05/17

High tea @ F.C. We dressed up with hats and pearls. Used china cups. I took one I knew had come to Canada from Japan. 3 pics



4

6+7 Out for a drive with a friend





-Mark at computer, Lots of work
to do



#1

#1

Me, I am Oneida, Bear Clan, This is me
in front of the longhouse were we observe
our place in this creation by ceremony, feasts,
socials, weddings, funerals, condolences,
naming of our babies



#15

15
A
~~#16~~

Canatara Park, Point Edward, Ont.
on Lake Huron



1 South Street double exposure - where I had dialysis the first time







11

My computer room. Far end is my Agfa flatbed scanner which I used when I was in business. I can scan anything that will fit on the scanner bed including black and white negs, colour negatives and slides. I have scanned over 5,000 family pictures. next is my two Mac computer systems, HP two sided colour printer, Lexmark two sided black ink printer. I scanned this record sheet.



49 FEELING USEFUL AGAIN





Dr. Arsh Jain was the wonderful Nephrologist that I was fortunate enough to have to manage my kidney disease.

When it came time that I needed Dialysis, Dr. Jain introduced me to his outstanding staff. Terri McCallum, the Renal Program Nurse Case Manager, and Tammy Willert, the Social Worker for the Renal Program provided invaluable counseling. These wonderful ladies guided me through the practical, mental, emotional and physical decisions involved in making the right decisions for my kidney care.



#8 This is my electric chair,
which helps me to travel INDEPENDENTLY.



My Ancestors - Who lived for me



1
+
2

A day to enjoy with a friend getting
our toes done! Much better



5 + 6

THE SWEET FACE THAT IS THE FIRST THING I SEE
EVERY MORNING.





September 18
Equipment
Dialysis

I used small equipment from dialysis unit. They had better results. These are small items used daily for dialysis.





4
(Sunsets) I love sunsets I get lost in them. I look
up at the skies / sunsets & pray. I get lost in
the beauty and think about life when
dialysis and my transplant is over



|| light

|| ^{light} Random tree pic. my back yard.



USB
Sept 19, 2020
cycling in Barrie

Conclusion

We were fortunate to have been welcomed into the lives of these study participants who were willing to share their experiences with their kidney disease and treatments. Participation in this study demonstrates a certain resilience and a desire to share, educate, and give thanks for their experiences. In some cases this was a solo project, and in other instances participants had willing partners to assist in their image-making. For instance, Ann is the beloved partner of Tony, one of our participants who has sadly passed on. Ann writes:

“The pictures give an overall picture of life on dialysis, [and] they were fun to take. Tony and I had enjoyed taking ours, I would guess all the recipients did because there were some great pictures taken. Tony always felt it was so important for people that were either starting or on dialysis to have the information needed. There is so much available but it is sometimes hard to find. If the journal can help in this regard it would make the transition into this scary stage in life a little easier. So the more information made available the better. It took Tony a couple of years to find out about the camp in Dorsett. When we were there we felt it was so under utilized. It was a wonderful place to go and relax and get treatment. Also the dialysis at sea is another holiday not well known. These things make a dialysis patients life so much better.”

When initially approached, some participants were apprehensive: a number claimed their lives were not particularly exciting and so they expected there would be many photos of their pillows, pets, or apartments. However, once engaged with the study, participants became intently aware of their environments and created insightful and comprehensive images. Many came to express, both in words and through imagery, that there is richness present in their lives. They share a true appreciation for their experiences and their loved ones, and they take time to acknowledge these gifts.

Images hold a number of meanings, depending on the viewer. A chair or bed could be viewed as a space of rest or restriction; quiet times can be interpreted as indicative of peace or isolation. As we've witnessed, the most familiar objects (often taken for granted) can always be viewed anew and in unfamiliar, novel ways.