



STEVE HOLMES

Cholangiocarcinoma
Australia (CCA)

FOUNDER

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CCA BRIEF DESCRIPTION

A centralised Information resource that lays down a foundation that contributes to improved patient outcomes. We ensure that patients and their caregiver community are educated, equipped, and empowered with today's latest medical breakthrough information - today! We connect and build community around this effort

KEY CCA PILLARS

Visibility & Voice

Connection & Sharing

Educate, Equip, Empower

Open, Aware, Willing

Character, Talent Potential

PATIENT DETAILS

www.steveholmes.net.au

GENERAL BUSINESS DETAILS

www.steveholmes.net.au/about

CCA AUSTRALIA

www.cholangiocarcinoma.com.au

- CCA Patient Toolkit
- CCA Digital Patient Introduction
- Resource & community
- Patient Mentor (AU, NZ & Global)

ASSOCIATIONS

- Cholangiocarcinoma Foundation (USA)
- CCF 2021 Sub-Steering Committee
- CCF Conference Salt Lake City
- CCA NZ
- AMMF UK

The Globally Connected Patient

Functioning at the intersection of Medical Science, Healthcare Providers & Patient Knowledge.

OVERVIEW & FOCUS

The pathway back to health

Enhancing the Cancer Toolkit Series a resource specifically tailored for the patient, and their caregiver support community is my central priority. There is so much more information available that I want to improve and add to this resource initiative that I know will help people on their journey. But more than anything I want to make this information resource incredibly easy for the newly diagnosed patient and caregiver community to find and use - it will improve outcomes and in some cases save lives.

Cancer Triggers:

Stress-related illnesses like irritable bowel syndrome and inflammatory bowel disease, have continued to surge over the past few decades. The underlying cause of these and other stress-related diseases involves a complex interaction between genes and environment. In response to stressor events, many genes are rapidly turned "on" (activated) or "off" (down-regulated /silenced).

Communication:

There are many breakthrough medical events occurring in the understanding of these triggers, but information channels to the Newly Diagnosed Patient remain clogged and disenfranchised.

Outcome Focused:

This intersection between Medical Science Breakthroughs, Professional Healthcare Providers, and the Newly Diagnosed Patient provides the greatest and most immediate opportunities for improved patient outcomes. As a grassroots patient-up-driven initiative, reshaping this information delivery and education of this is my primary focus.

Patient Support and Resource Priorities

1. Cholangiocarcinoma Australia Foundation
2. Patient ToolKit distribution pipeline to "Point of Diagnosis"
3. Register of current CCA Skilled professionals (Heat mapped)
4. Register of available clinical Trials
5. Molecular Profiling Education
6. Register of Mutations and treatment options
7. Telehealth for patients and caregivers

Next Steps

- Mentorship Register & Training
- Localised Patient & Caregiver Events
- Trusted Partners
- Targeted programs that fund in Grads & Clinical trials
- Inaugural Annual CCA Event

Key areas of milestones for CCA Australia

1. Resource & Visibility
2. Voice, Connection & Sharing
3. Educate, Equip & Empower
4. Open, Aware, Willing
5. Talent, Character & Potential

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Key areas of milestones for CCA Australia
This is our current road map

01

Centralised AU Patient & Caregiver Resource with easy access

02

Centralise AU Peer to Peer Patient & Caregiver Community

03

Newly Diagnosed Patient & Caregiver Introduction Toolkit

04

Integrate CCA Community with Global Patient Communities

05

Integrate CCA Medical & Science Community with Patient Community

ABOUT STEVE

www.steveholmes.net.au

Up Close and Personal

Ex Waikanae NZ, Married, 2 Children, Road Cyclist, Running, Rugby

Fun Fact

A road accident whilst in the lead breakaway of the GC100 road cycling event on the Gold Coast Australia.

The entire breakaway (25) went to ground, I broke my neck (c6) which left me paralysed down my right side for 9 months.

On my first training ride back 11 months later & against the better judgment of my wife, I am back on my bike riding with my group when out of the blue - a head-on with a kangaroo in the pitch black of a 5:30 am training ride. The Roo landed on my handlebars. The result - A busted bike and a black eye from where our heads banged together eye to eye. YES true as a Roo's tale!

STEVE'S PATIENT OVERVIEW

2016 to present

- Extrahepatic - Distal - Outlook < 6 months
- 2017 July Stage 4 Significant Mets to Liver, Diaphragm and both Lungs
- Clinical trial: Attica via Royal Brisbane
- Clinical Trial: Merck's Keynote 158 - 2017 to present via Royal Brisbane - achieved a dynamic complete and full response. NED - ongoing since October 2017 to Present (2nd of 3 globally as at 2021)

Surgery Total 25 hrs

Includes 13 hr Whipple removing

- Bile Duct (95%),
- Gall Bladder (100%),
- Stomach (80%),
- Pancreas (33%)
- Duodenum (100%),
- Lymph Nodes (2).

Complications

1-month post-Whipple: Significant Aneurysm Event to Main Hepatic artery.

Prior Medical

- Anaphylactic Shock
- Bell's palsy
- Broken Neck C6 - Paralysed right side 9 months

Family

- Younger brother (RIP 2014) Exact same CCA diagnosis as myself