

Impact of the Cholangiocarcinoma Foundation's *Newly Diagnosed* Program



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Background

What is Cholangiocarcinoma (CCA)?

CCA is cancer of the bile ducts. Per the Cholangiocarcinoma Foundation (CCF), approximately 10,000 people are diagnosed each year; 2/3 of patients are diagnosed at 65 or older.

According to the **American Cancer Society**, the 5-year survival rate with early diagnosis is 25%. If the cancer has metastasized, this drops to **<5%**.

Patients can wait a long time to be diagnosed, be misdiagnosed, or their provider may not be familiar with options/treatment. **>50%** of CCA patients experienced anxiety and depression regarding diagnosis (Bibeau et al., 2021).

Access to timely and educational resources could provide support.

In September 2021, CCF began the *Newly Diagnosed* program.



Overview of the *Newly Diagnosed* program

The program includes:

- 8 email series (includes initial and closing surveys)
- Motivational Videos
- Patient and Caregiver Care-Kits
- (Optional) Patient Advocate One-on-One Zoom call
- (Optional) Opportunity to join *Peer Mentor Program*



Participants and Recruitment

1,075 participants have completed registration for the CCF *Newly Diagnosed* email series and received their Care-Kit.

- 670 Patients
- 405 Caregivers

Diagnosis Sites

- Intrahepatic (n=512)
- Perihilar (n=64)
- Distal (n=54)
- Unsure (n=445)

How Patients Found Us

- Google (n=423)
- Family member or friend (n=181)
- Physician (n=99)
- Other (n=43)
- Facebook (n=301)
- Instagram (n=12)
- YouTube (n=7)
- Twitter (n=7)
- LinkedIn (n=2).

Challenges

- The first email was viewed by 72.1% (n=854) of 1185 recipients, while the final email was viewed by 48.4% (n=507) of 1048 recipients.
- So far, only 17 (3.4%) out of 507 persons who opened the last email completed the closing survey.



Takeaways

- Among participants who opened the first email, 328 (38.4%) participated in the initial survey.
- Participants confirmed a lack of educational and emotional support surrounding their diagnosis.
- The closing survey responses indicate that email series positively impacted participants' education.

Revised Intervention

- To increase rate at which patients receive information, and reduce reading burden, the email series was reduced from **8** to **4** emails.
- To better gather information regarding patient experiences, the Care Kits will be sent following *completion* of the initial survey
- We will continue to promote and provide one-on-one Zoom sessions and Peer Mentor program.

Special thanks to all the patients and caregivers. Together we are creating a better future for individuals diagnosed with Cholangiocarcinoma.