

ASSOCIATION OF  
CANCER CARE CENTERS

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**ADVANCING  
CAR T-CELL THERAPY CARE  
CONTINUITY AND COLLABORATIVE  
PATIENT EDUCATION**

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Summary of a Working Summit



## INTRODUCTION

Chimeric antigen receptor (CAR) T-cell therapies offer the promise of increased disease-free survival to patients with relapsed/refractory hematologic malignancies.

As of 2023, there are 6 FDA-approved therapies available to treat patients with certain types of hematologic malignancies, and CAR T-cell therapy remains a rapidly evolving treatment option.

The Association of Cancer Care Centers (ACCC) has developed numerous education programs to support the multidisciplinary care team in staying up-to-date on the CAR T-cell therapy landscape, including best practices for planning and implementation. Yet, gaps remain in the understanding of patient and caregiver education and experiences with CAR T-cell therapy; further, improving community oncology education and enhancing collaboration between referring community providers and accredited treatment centers can optimize timely patient identification and referral as well as streamline access to therapy and care continuity.

### *Examining Continuity of Care and Experiences of Patients and Caregivers*

CAR T-cell therapy involves several complex stages of care and transition between providers. To be considered for therapy, a patient must be referred to a certified CAR T-cell therapy center for a comprehensive clinical evaluation, financial assessment, and logistical examination. To receive treatment, the patient must have a dedicated caregiver available 24 hours per day, both the patient and caregiver must stay within a 2-hour/30-mile radius of the treatment center during outpatient treatment, and both must remain near the facility for the first 30 days after treatment. Following the first 30 days, the patient returns home and resumes care through the team at the referring program.

To better understand current coordination practices, experiences, and opportunities to optimize care, ACCC conducted a series of virtual focus groups and interviews between September and November 2023. Three focus groups and 1 interview involved 23 health care professionals and staff; these participants work in cancer programs/practices and provide care for patients with hematologic malignancies who may be eligible for or who are receiving CAR T-cell therapy.

The remaining focus group was comprised of 7 patients who received CAR T-cell therapy and caregivers. All participants provided recommended opportunities for ACCC and its partners to increase access to CAR T-cell therapy and support for patients and caregivers.

#### **Two key, immediate opportunities emerged from the groups:**

- 1** Continue to build capacity and infrastructure to support early patient identification and optimize continuity of care across sites.
- 2** Address patient and caregiver needs by facilitating clear, multidirectional communication between patients, caregivers, providers, and patient advocacy groups to improve health outcomes.

## A VIRTUAL SUMMIT

To move these opportunities forward, ACCC—with its program partners Cancer Support Community (CSC), the Association of American Cancer Institutes (AACI), and the Advanced Practitioner Society for Hematology and Oncology (APSHO)—convened a virtual summit of multidisciplinary cancer care professionals, patient advocacy representatives, and other stakeholders in February 2024. The goal was to examine best practices and identify calls to action to support:

- Timely identification and referral of patients for CAR T-cell therapy
- Care continuity between referring programs and certified CAR T-cell therapy treatment centers
- Patient and caregiver needs.

The 33 summit participants included oncologists, advanced practice providers, nurses, nurse navigators, pharmacists, financial navigators, administrators, social workers, representatives from patient advocacy organizations and partner associations.

This summary provides highlights from the summit as well as resulting calls to action.

### A Patient's Experience

The summit opened with a brief video from Judith Harding, a patient who shared her personal experience about undergoing CAR T-cell therapy. She called attention to the financial and logistical challenges of finding a dedicated caregiver to become eligible for care:



*When I was told I was going to be on the CAR T [-cell therapy] list, I realized this was going to be pretty much a last resort. It's assumed everyone has a dedicated caregiver, but I realized I was not going to be able to fulfill that requirement. I wrote a long email to my oncologist and asked to be taken off the list. They did not take me off the list.*

*There was no assistance from anyone on my health care team on finding a caregiver. Almost at the very last hour, I was able to find a home health aid agency.*

*I managed to put together the close to \$10,000 the agency required for the 30 days. I will be celebrating [survival] of not only 16 years with multiple myeloma, but also 1 year after CAR T [-cell therapy].*

## Real-World Applications: Collaborative Care Delivery

The summit provided a platform for participants to discuss current practices in collaborative care. Opening remarks were delivered by co-chairs Amy D. Smith, FNP-BC, the director of the Meredith & Jeannie Ray Cancer Center at Ivinson Memorial Hospital in Laramie, Wyoming; and Caron Jacobson, MD, MMSc, medical director of the Immune Effector Cell Therapy Program at Dana Farber Cancer Institute and associate professor at Harvard Medical School in Boston, Massachusetts.

*"This summit is timely, because despite increasing numbers of studies demonstrating the power and the benefit of CAR T [-cell therapy] in multiple cancers—including randomized studies, which are demonstrating improvements in overall survival—we are still only reaching a fraction of patients. It is not just that patients are not coming to CAR T [-cell therapy] centers, but there are gaps, even when patients get to CAR T [-cell therapy] centers. So it really goes both ways. I think through our work today, we can improve on both sides—access and the patient experience."*

**- Caron Jacobson, MD, MMSc,**  
Summit Co-Chair



## "IF THEY RECUR, YOU SHOULD REFER"

### CAR T-Cell Therapy Consult Considerations for Patients with Large B-Cell Lymphoma (LBCL)

# R



#### RELAPSED/ REFRACTORY LBCL

Any patient with relapsed or refractory LBCL should be referred for consult

# E



#### EVERY AGE AND COMORBIDITY

Age and comorbidity should be evaluated on a case-by-case basis by a CAR T-cell therapy specialist

# C



#### CAREGIVER SUPPORT

Discuss the need for support and continuum of care throughout the patient journey

# U



#### URGENCY TO RECOMMEND CONSULT

Rapid identification and referral of patients for consultation is necessary for timely evaluation

# R



#### RECEIVE PATIENTS RETURNING POST- CAR T-CELL THERAPY

Streamline communication across teams within the local network to optimize local care of patients returning after CAR T-cell therapy



1. Riedell PA, Downs C, Boehmer L, Ebmeier J, Porter D, Williams A. If they RECUR, you should refer: A community oncologist patient ID roundtable summary. *Transplant Cell Ther.* 2024;30(1):14-16. doi:10.1016/j.jtct.2023.10.019

### Timely Patient Identification in a Community Setting

Smith was joined by David L. Porter, MD, director of Cell Therapy and Transplant and the Jodi Fisher Horowitz Professor in Leukemia Care Excellence at Penn Medicine in Philadelphia, Pennsylvania, in presenting information on the importance of identifying and referring patients early for evaluation at centers that provide CAR T-cell therapy.

Porter discussed a new framework, RECUR<sup>1</sup>, that was developed collaboratively by ACCC, AACI, and the American Society for Transplantation and Cellular Therapy (ASTCT) to identify and refer patients. He stated, "We [believed] there had to be an effective framework to identify patients who have LBCL for CAR T [-cell therapy]. We wanted to provide clear guidance but not be overly restrictive to both the care team and patients. We wanted to emphasize that early patient identification would increase the chance of referring eligible patients and referring them in time to optimize outcomes. We developed a tagline and acronym 'If they RECUR, you should refer' to encompass the referral of all patients with relapsed lymphoma to a CAR T [-cell therapy] center."

Smith discussed how they put this framework into practice at Ivinson Memorial Hospital. Ivinson, a 99-bed hospital located in rural Wyoming, has 1 hematologist/oncologist on staff and 7 outpatient infusion chairs. Ivinson does not offer inpatient chemotherapy services. The health care team at Ivinson has established relationships with those at larger academic medical centers to increase access to innovative treatments and allow care close to patients' homes. Smith outlined their processes for CAR T-cell therapy and discussed the importance of collaboration and timely referrals using a recent patient example:

1. A patient was referred to Ivinson and was seen quickly in clinic by the hematologist/oncologist.
2. After the initial visit, Ivinson staff members were able to schedule an appointment for the patient to be seen 3 days later at the University of Colorado Anschutz Medical Campus (CU Anschutz) in Denver, Colorado.

- Initial diagnosis was confirmed with the team at CU Anschutz and a treatment plan was developed.
- The patient received chemotherapy at Ivins. The CU Anschutz team continually monitored the patient in collaboration with the Ivins team.
- Following treatment, the patient experienced a disease recurrence.
- The Ivins team immediately initiated a referral to evaluate the patient for CAR T-cell therapy at CU Anschutz.

- Upon approval, the patient received CAR T-cell therapy at CU Anschutz and returned to Ivins 30 days after completing the treatment.
- Staff at Ivins continue to deliver supportive care to the patient.

Smith concluded, "There were a lot of things we coordinated and had the confidence from the Anschutz team to do care here. It was also helpful to know that we could reach out to the Anschutz team at any time, which was huge, because it also gave the patient more confidence."

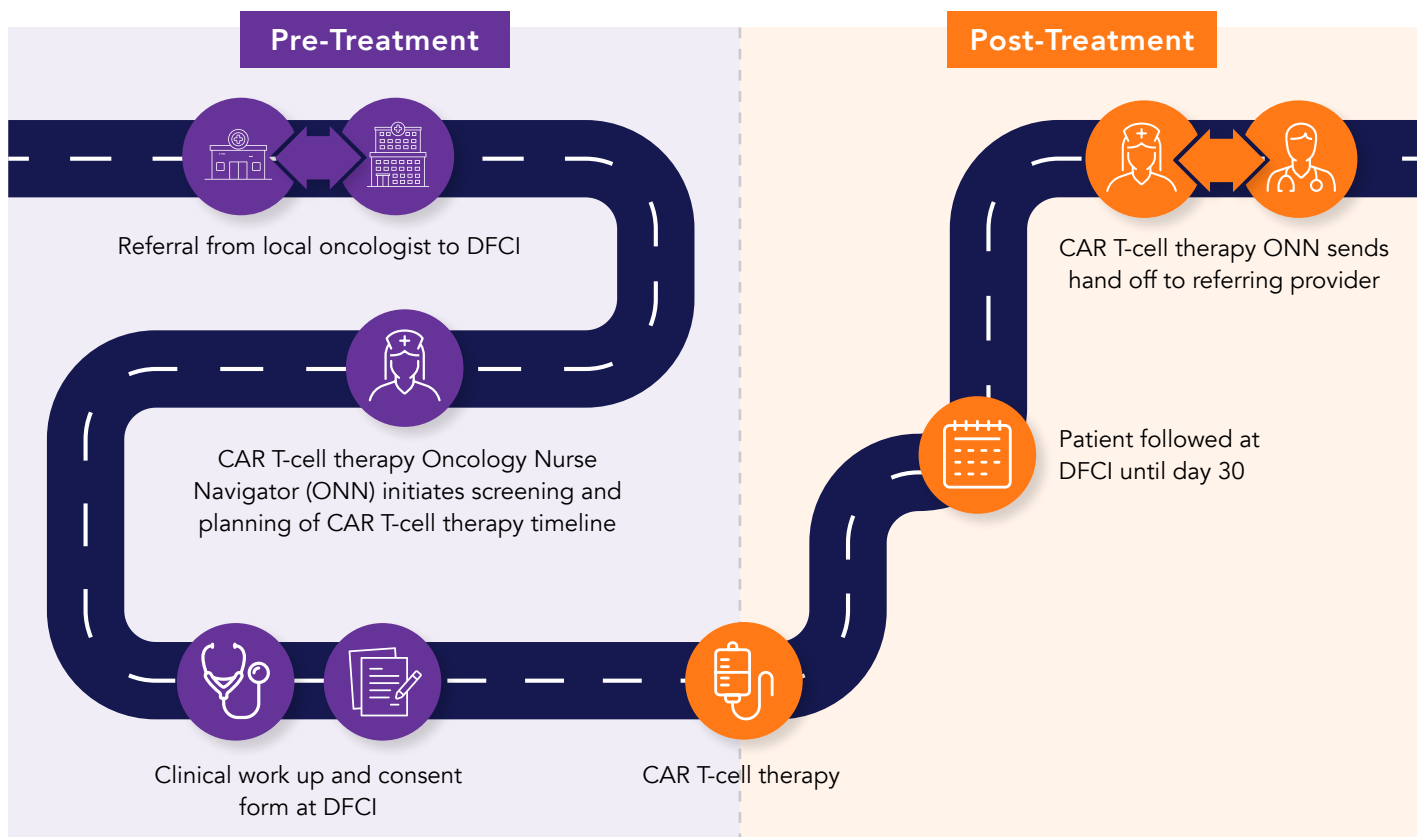
## Building Care Continuity Across Sites

Co-chair Caron Jacobson was joined by Lauren Desnoyers, RN, BSN, an oncology nurse navigator at Dana Farber Cancer Institute; and Mihir Raval, MD, MPH, a hematology specialist at New York

Oncology Hematology–Albany Medical Center in Albany, New York; in presenting a case study to illustrate how care continuity is achieved from point of referral to the return home.

## Successful Care Coordination

Example from Dana-Farber Cancer Institute (DFCI)



### **Key Elements That Facilitate Care Continuity**

Panelists discussed key elements that improve continuity between the local care team, CAR T-cell therapy center, and the patient and caregiver. Important elements include:

- Engagement of the multidisciplinary local oncology care team
- Presence of a comprehensive CAR T-cell therapy team at the treatment site
- Open channels of communication between referring provider, patient, caregiver, and family
- Ongoing, multidirectional communication between the referring provider and the CAR T-cell therapy team throughout all stages of care
- Provision of monitoring and supportive care following CAR T-cell therapy.

### **Helpful Resources from a CAR T-Cell Therapy Center**

The Dana Farber team presented elements included in their care hand-off letter and packet provided to local care centers. The goal of providing these materials is to ensure a smooth transition of care when patients return home. Elements include:

- General instructions for the long-term management of treatment effects (eg, infection prophylaxis, management of cytopenias, cytokine release syndrome, and neurotoxicity) following CAR T-cell therapy
- Routine follow-up recommendations
- FDA-mandated reporting requirements
- Important contact information for the Dana Farber team
- PET scan results at 30 days following CAR T-cell therapy and provider progress notes
- Recent laboratory results and a hospital discharge summary that includes more details about clinical course during admission for CAR T-cell therapy.

## **Calls to Action**

Common themes emerged from participant breakout groups that addressed patient and caregiver needs related to education, communication, and continuity of care. Actions that could be implemented at a local, regional, or national level include:

- 1** Increasing peer-to-peer learning opportunities to help build trust, relationships, and share best practices between staff at referring programs and treatment centers. Providing in-person, regional collaboration and formalizing organizational relationships with standardized bidirectional communication and processes can facilitate early patient identification and care continuity.
- 2** Leveraging patient advocacy groups to provide patient and caregiver support, education, and connections to other community resources. Development of partnerships with trusted patient organizations can facilitate ongoing education, social/emotional support, and access to resources before, during, and after treatment.
- 3** Increasing engagement with patients and caregivers to provide education and support services across the care continuum of CAR T-cell therapy. The entire multidisciplinary team—including social workers, pharmacists, nurses, navigators, and financial advocates—should be used at multiple points in time to ensure that patient and caregiver needs are being met. Educational resources should be easy to read, understand, and act on and be available in languages other than English.

## Conclusion

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As further approvals of CAR T-cell therapies are anticipated to manage more cancer types, staff at referring programs and treatment centers must have opportunities to connect. Furthermore, they need resources to facilitate smooth care coordination across the continuum and meet the needs of patients and caregivers to optimize outcomes.

*"I think that more opportunities for sharing information/ lessons learned with colleagues in places like this Summit opens up so many learning opportunities for us to improve our patient care!"*

- Summit Participant



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In partnership with:



This program is made possible with support from:

