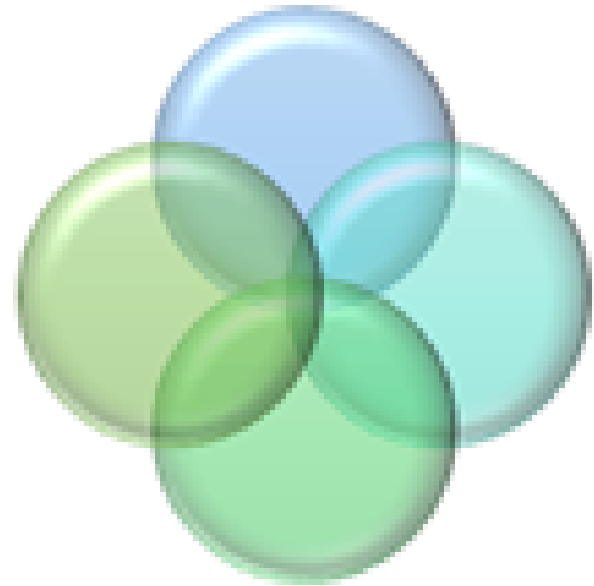


CHAMPION Care Action Team

Wednesday, 5 November 2025

Today's Discussion

- Welcome
- Identifying barriers/challenges
- A focus on technology
- Reminder of next steps
- Upcoming calendar of meetings





CHAMPION Care: Barriers

Identify our most significant challenges/barriers

When developing a solution, we need to consider the barriers that could prevent our success. These barriers will also drive funding needed to ensure success. Are the topics listed below accurate? What else might we be missing?

Nursing staff	<ul style="list-style-type: none">• Not enough trained pediatric RNs to serve CT children - Lack of skilled pediatric hospice RNs, Shift nurses receive low pay so disincentive to do shift work
Certification & Licensure	<ul style="list-style-type: none">• No state-based minimum Certifications/Licensures – there are efforts in process with CT DPH Working Group to define baseline certifications
Geographic access	<ul style="list-style-type: none">• Not enough certified facilities across CT that can accommodate children with life-limiting illnesses and/or who offer pediatric palliative and hospice care
Hospice parameters	<ul style="list-style-type: none">• Hospice care definitions impact and/or limit offering concurrent & palliative care<ul style="list-style-type: none">◦ Dr designation of 6 or less months/failure to thrive which drives medical/care parameters and doesn't allow for pediatric concurrent care options – there's an insurance impact which limits access to concurrent care as medical coding follows hospice designation
Limited continuity	<ul style="list-style-type: none">• Inconsistent connections between medical community, hospice providers, case managers, etc;• Breaks in coordination between facility and transition to home
Awareness of available resources	<ul style="list-style-type: none">• Family testimonials/experiences/needs tell us about their challenges trying to get the best information and to navigate the medical system with the goal of getting the right services and support when they most need them• Lack of awareness of available resources, both with the medical community, families, facilities, etc
Payment/reimbursement structure	<ul style="list-style-type: none">• Care and services Issues because of confusing medical coding, insurance companies' approvals/reimbursements

Technology & Education

Using online solutions to support our families and their needs



It's likely that parents of children in CT range in age from 20-45 and the virtual world is a place that they frequently utilize for many daily needs. Effective technology can aggregate and curate information to allow parents to learn about their child's condition, to find skilled resources that can help them and allow them to feel a greater sense of comfort and control.

One example of an App is 'Perplexity', an AI Search and Chat solution, which aggregates and curates sources of information - but there are many others which offer similar aggregator/curation portals to help parents. As we build out CHAMPION Care education, we need to consider technology solutions that include information about the CT program and focus curation of content that is best for our families.



Perplexity - AI Search & Chat

Ask. Research.
Trusted Answers

What are treatment options if my child has T-cell childhood acute lymphoblastic leukemia

Perplexity Images

Treatment options for T-cell childhood acute lymphoblastic leukemia (T-ALL) typically involve a multi-phase approach primarily based on chemotherapy, with additional treatments tailored to the child's

Ask a follow-up

Searching the web

SEARCHING

T-cell childhood...

READING 10

- leukemiarf
- seattlechildrens
- ashpublications
- uchicagomedicine
- cancer
- stjude
- nih
- ashpublications
- cancer
- bloodcancerunited

Sources

- T-Cell Lymphoblas...**
T-cell lymphoblastic leukemia (T-ALL) is a typ...
Leukemiarf
- Relapsed Acute Ly...**
Learn about treatment options for acute lymph...
Seattlechildrens
- How I treat newly...**
Historically, these aggressive T-cell malign...
Ashpublications
- Pediatric Cellular I...**

Images

CHAMP Care: Reminder of Tasks Ahead

List of key benchmarks/elements needed for Feb Report to Assembly



Our deliverables for the next few months to prove the need will require:

Program definition

A description for what this program will look like, how it will be structured, what resources will be needed to move this forward, recommendations for a phased launch

Education & awareness

What we'll communicate, who we need to impact, exploring ways to deliver this

Data gathering

Discussions with all sources to confirm scope of need, details on costs/metrics that will flow into the program description to prove the need

Resource assessment

What people and technologies will be needed to move ahead, what will it cost to engage these resources

Scenario development

Create examples of pediatric situations that include costs, complexity of need, family testimonials to prove the need

Today's Discussion

Questions, Comments, Recommendations



Upcoming Meetings

(Calendar Invitations & Links Forthcoming)

Report Deadline

Action Team	Advisory Group	Feb 6, 2026
NOV <ul style="list-style-type: none">• 11/12 – 1-2 p DEC <ul style="list-style-type: none">• 12/3 - 1-2 p• 12/10 – 1-2 p JAN <ul style="list-style-type: none">• 1/7 - 1-2 p• 1/21 - 1-2 p FEB <ul style="list-style-type: none">• 2/4 - 1-2 p	NOV <ul style="list-style-type: none">• 11/19 - 1– 2:30 p DEC <ul style="list-style-type: none">• 12/17 - 1– 2:30 p JAN <ul style="list-style-type: none">• 1/28 - 1– 2:30 p	<ul style="list-style-type: none">• Final proposal is due to the CT Assembly by Friday, Feb 6, 2026 