



St. Jude Family Voice FAQ

- **What is St. Jude Family Voice?**

St. Jude Voice is a virtual advisory community for the caregivers of patients in active or post treatment. The entire community is online. You can take part as an adviser anytime, anywhere using your computer, tablet, or phone. The goal of St. Jude Voice is to learn from your family's experiences and share that information with St. Jude staff and other families to improve patient care. Within St. Jude Voice, there are two different communities: St. Jude Family Voice and St. Jude Legacy Voice. Read below about the different communities so you know which community is right for you.

- **What is St. Jude Family Voice?**

St. Jude Family Voice is a virtual advisory community for the caregivers of patients in active or post treatment.

- **What is St. Jude Legacy Voice?**

St. Jude Legacy Voice is a virtual advisory community for the bereaved families of St. Jude patients.

- **How do I join St. Jude Voice?**

To Join St. Jude Family Voice - Go to www.family-voice.stjude.org/c/r/JoinFamilyVoice to get started right away or send an email to pfcc@stjude.org and let us know you want to join this group. We will need your name and email address to start.

To Join St. Jude Legacy Voice - Go to www.legacy-voice.stjude.org/c/r/JoinLegacyVoice to get started right away or send an email to pfcc@stjude.org and let us know you want to join this group. We will need your name and email address to start.

To move from St. Jude Family Voice to St. Jude Legacy Voice - Send an email to pfcc@stjude.org. Let us know your name and the email address you have used with St. Jude Family Voice. Then, tell us in the email that you would like to change communities. Please do not need to unsubscribe from St. Jude Family Voice in order to move to St. Jude Family Voice.

- **How do I unsubscribe from St. Jude Voice?**

If at any time you are no longer interested in being part of St. Jude Voice, click the unsubscribe button at the end of any email, survey, or St. Jude Voice webpage.

- **How do I take part in the St. Jude Family Voice community?**

You can share your voice in three ways:

- **Surveys:** Regularly answering surveys or “activities” is a big part of St. Jude Voice. Surveys are created in partnership with St. Jude staff members. By answering survey questions, you are providing needed feedback to people who want to put helpful ideas into action.
- **Forums:** At scheduled dates and times, we will host live online forums. You will have a chance to hear from St. Jude staff or advisers. During the forum, you might answer questions, take polls, or take part in a chat. Forums are a great way to share your voice.
- **Visiting the Hub:** The Hub is the main webpage for St. Jude Voice. On this webpage, staff will post information, newsletters, links, articles, videos, surveys, survey feedback, and more to keep you up to date on the latest St. Jude news. Many items posted on the Hub will lead you to other opportunities to engage with St. Jude.

St. Jude Family Voice Hub: www.family-voice.stjude.org/hub

St. Jude Legacy Voice Hub: www.legacy-voice.stjude.org/hub

- **How do I update my St. Jude Voice profile information, change my email address, or change my password?**

- **Change your profile information:** Visit the hub at www.family-voice.stjude.org/hub or www.legacy-voice.stjude.org/hub. In the upper right-hand corner of your screen, click the circle with your photo in it. A white

pop-up box will appear listing your user name and two options: “Account Settings” and “Sign Out”. Click “Account Settings” to go to your user profile. Here you can edit your name, username, title, bio, profile background, and profile photo.

- **Change your email address:** Once you get to your profile as described above, you will see a space to enter your email address. You can enter your new email address here.
- **Change your password:** Get to your user profile as described above. Look at the top left of the profile page. You will see the words “Profile,” “Password,” and “Connected Accounts.” Click on the word “password.” A new page will open and you will see instructions for how to change your password.

You can always email support@family-voice.stjude.org or support@legacy-voice.stjude.org if you have any trouble.

- **Can I link my St. Jude Voice account to my other social media accounts?**

Yes! You can link your St. Jude Voice account to your Facebook, LinkedIn, or other social media account. Visit the hub at www.family-voice.stjude.org/hub or www.legacy-voice.stjude.org/hub. In the upper right-hand corner of your screen, click the circle with your photo in it. A white pop-up box will appear listing your username and two options: “Account Settings” and “Sign Out.” Click “Account Settings” to go to your user profile. Look at the top left of the profile page. You will see the words “Profile,” “Password,” and “Connected Accounts.” Click “Connected Accounts.” A list of all the accounts you can connect to will appear. Select the ones you would like to connect to. You will need to login to each social media account you would like to connect.

- **How do I sign out of my St. Jude Voice account?**

Visit the hub at www.family-voice.stjude.org/hub or www.legacy-voice.stjude.org/hub. In the upper right-hand corner, click the circle with your photo in it. A white pop-up box will appear listing your username and two options: “Account Settings” and “Sign Out.” Click “Sign Out,” and you will be signed out of your account and taken to the St. Jude Voice login page.

- **What is a profile variable (PV)?**

A profile variable is something about you that tells us about who you are and the unique experiences you have had at St. Jude. Some examples of profile variables are your primary St. Jude clinic, your St. Jude housing, or even your birthday. We will use your profile variables to make sure we are only asking you questions about experiences you have had instead of asking you every question that crosses our minds. You are adding to your profile variables every time you take a survey.

- **How do I update my information and profile variables?**

If something changes, like you move from Tri Delta Place to Ronald McDonald House, you should update your profile variables. Just email us at pfcc@stjude.org and let us know what has changed. Some examples of profile variables that might change during your time at St. Jude are: Your clinic, your housing, and your experiences with different treatment areas or St. Jude services.

- **How do I refer other St. Jude families to join St. Jude Family Voice or St. Jude Legacy Voice?**

Have the interested adult caregiver send their name, email address, and community choice—Family Voice or Legacy Voice—to pfcc@stjude.org. Or, direct them to the St. Jude Voice website [here](#).

- **I started a survey but had to leave the survey before I completed it. How do I complete the survey later?**

You can return to the email inviting you to the survey and click the link again to open the survey back up. You can also click the link to the survey in any reminder emails you are sent.

- **I shared something in a survey that I wish to address with a St. Jude staff member personally.**

The survey results are not monitored by Patient Family-Centered Care staff throughout the time the survey is posted.

If a survey brought up any immediate needs for you, we encourage you to address your needs with your care team or call the main St. Jude help line at 1-866-2STJUDE (1-866-278-5833) where staff is standing by 24 hours a day, 7 days a week.

- **How do I contact Patient Family-Centered Care at St. Jude?**
Email us anytime at pfcc@stjude.org
- **How do I contact Quality of Life Services at St. Jude?**
Email Quality of Life Grief Support Coordinator Lisa Clark, PhD, at lisa.clark@stjude.org
- **Who do I contact when I have technical problems?**
Email your questions or needs to support@family-voice.stjude.org or support@legacy-voice.stjude.org. Screenshots and descriptions of the problem are always helpful.
- **What do I do if you didn't answer my questions here?**
If we didn't answer your questions here, we want to know about it! Email us at pfcc@stjude.org

St. Jude Family Voice and St. Jude Legacy Voice are safe places for families. Patient Family-Centered Care reserves the right to moderate participation and content as they see fit.



Patient Family-Centered Care