

ADV 18: Osteosarcoma Survivorship and Peer Support: Outcomes for Youth Leadership Initiatives

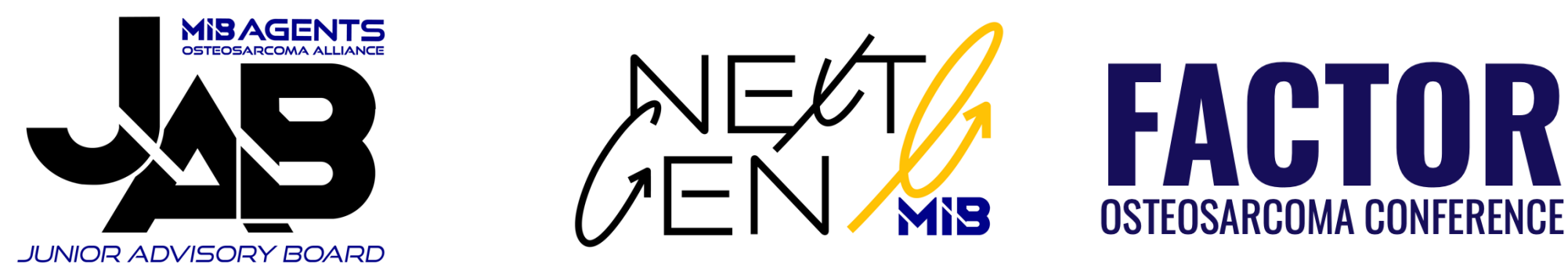
Max Penzer



Introduction

Osteosarcoma (OS) is the most common malignant bone tumor in children, adolescents, and young adults (AYAs), with approximately 400 individuals younger than 40 years diagnosed annually in the United States (1). OS treatment typically involves several rounds of intensive MAP chemotherapy and is often accompanied by debilitating side effects and long-term complications, such as limb amputation or impaired growth. While outcomes for localized disease approach 65–70% with multi-agent chemotherapy and surgery, patients with metastatic or relapsed disease have a 5-year overall survival of less than 30% (1). Troubles due to cancer do not end in remission, as survivorship is frequently marked by feelings of isolation, difficulty reintegrating into social environments, and a lack of connection with peers who share similar experiences (2). These challenges can impact emotional well-being, identity development, and overall quality of life for pediatric cancer survivors (2). In response, MIB Agents, a nonprofit organization dedicated to improving the lives of patients and families affected by OS, has created several youth-led initiatives that promote peer-to-peer engagement, mentorship, and advocacy. These programs support resilience by creating structured opportunities for shared experiences and community building, which have helped OS survivors cope with the obstacles encountered during survivorship.

MIB Programs



The Junior Advisory Board (JAB) is a 26-member community of OsteoWarriors and OsteoSiblings aged 15-20 who come together to share their voices, build friendships, and engage in advocacy to improve the outcomes for those touched by OS. Through leadership opportunities and a supportive community, the JAB gives advocates a space where they can feel heard and create meaningful change. The JAB started in 2020.

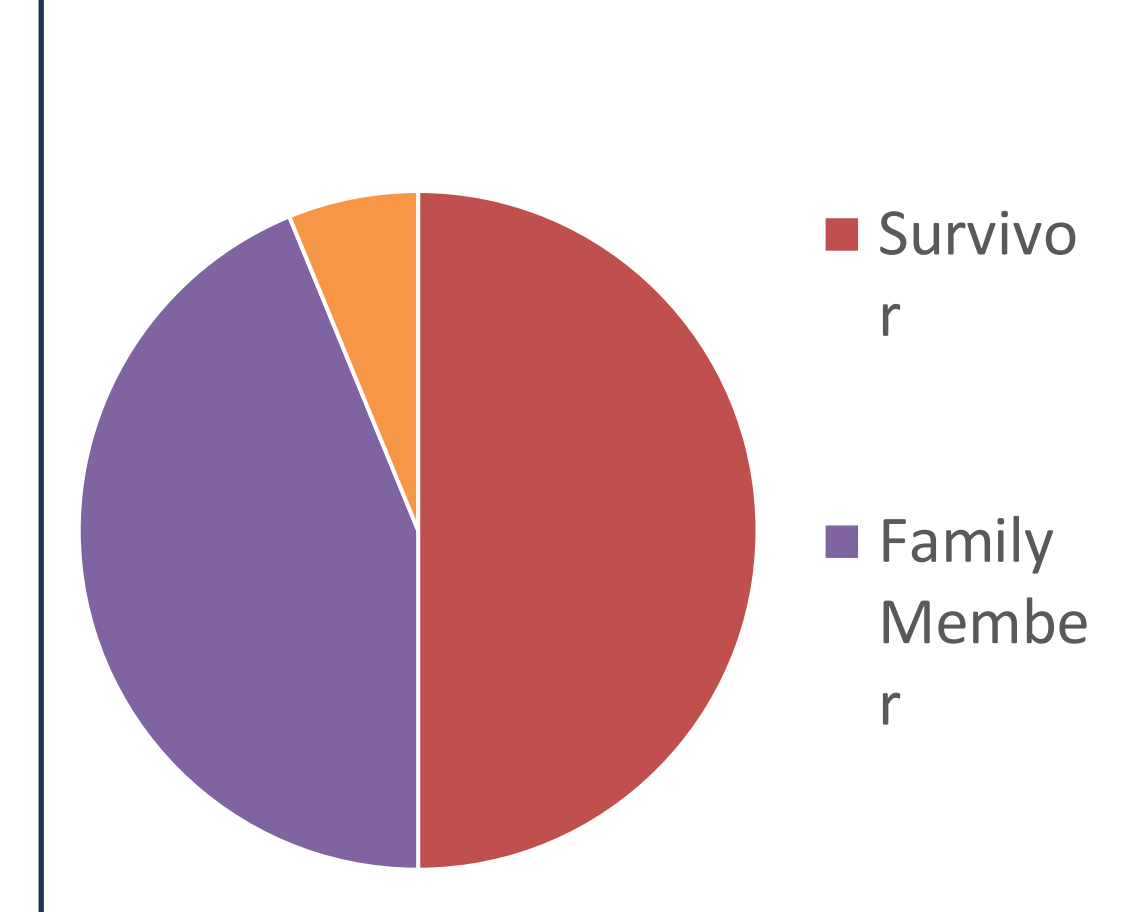
NextGen is a 13-member community of OsteoWarriors and OsteoSiblings aged 21-26 dedicated to making a difference in the osteosarcoma community. Members learn directly from physicians and researchers through mentorship, gaining real-world insight into research and advocacy. Alongside professional growth, NextGen emphasizes connection and shared experience, bringing together individuals passionate about learning, supporting others, and advancing MIB Agents' mission. NextGen started in 2025.

The annual MIB Agents FACTOR conference brings together the leading researchers, clinicians, and surgeons, along with patient families and OsteoWarriors, to Make It Better for those battling this disease. The OsteoWarriors HQ (headquarters) brings together kids and young adults who have a connection to OS. Connecting the kids who have lost limbs, friends, and siblings to OS is one of the most important things we do. It offers a chance to step away from the hospital and build meaningful connections with others who share similar experiences.

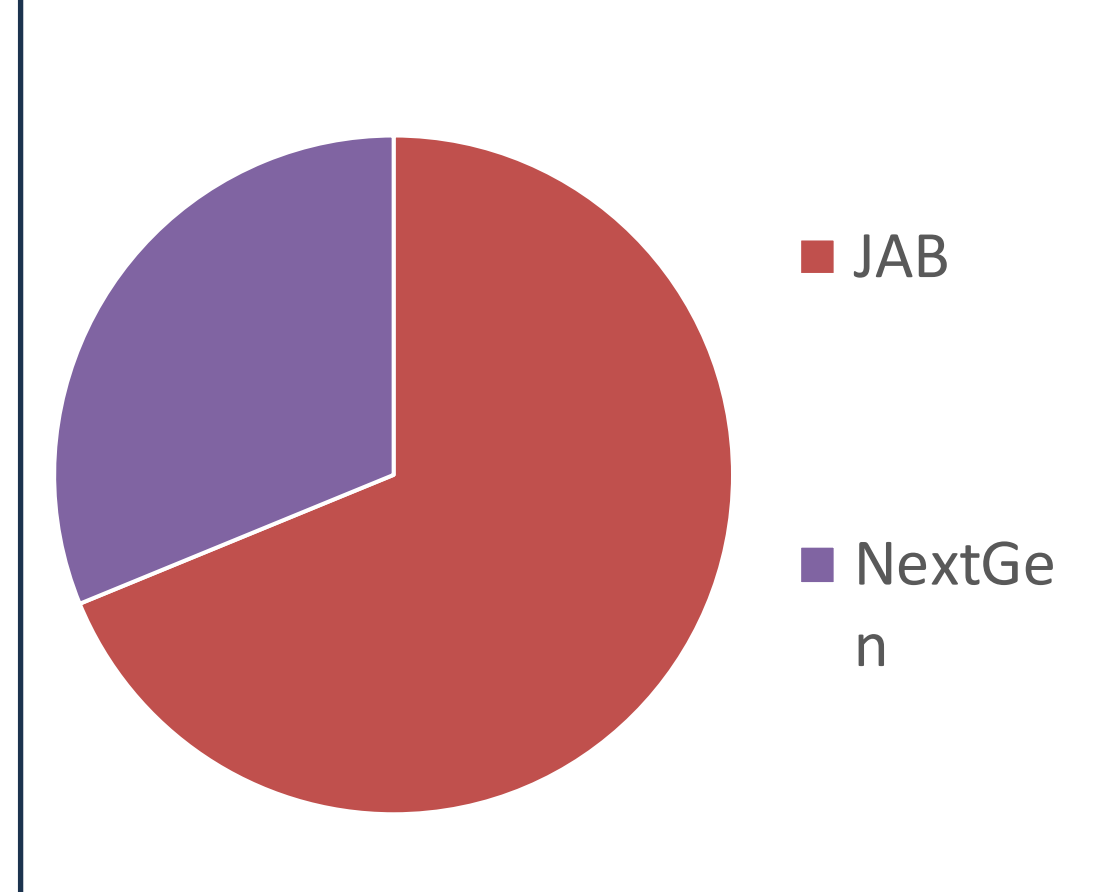
Survey Results (n = 16)

The survey was administered to the 2026 MIB Agents JAB and NextGen Cohort through the respective group chats.

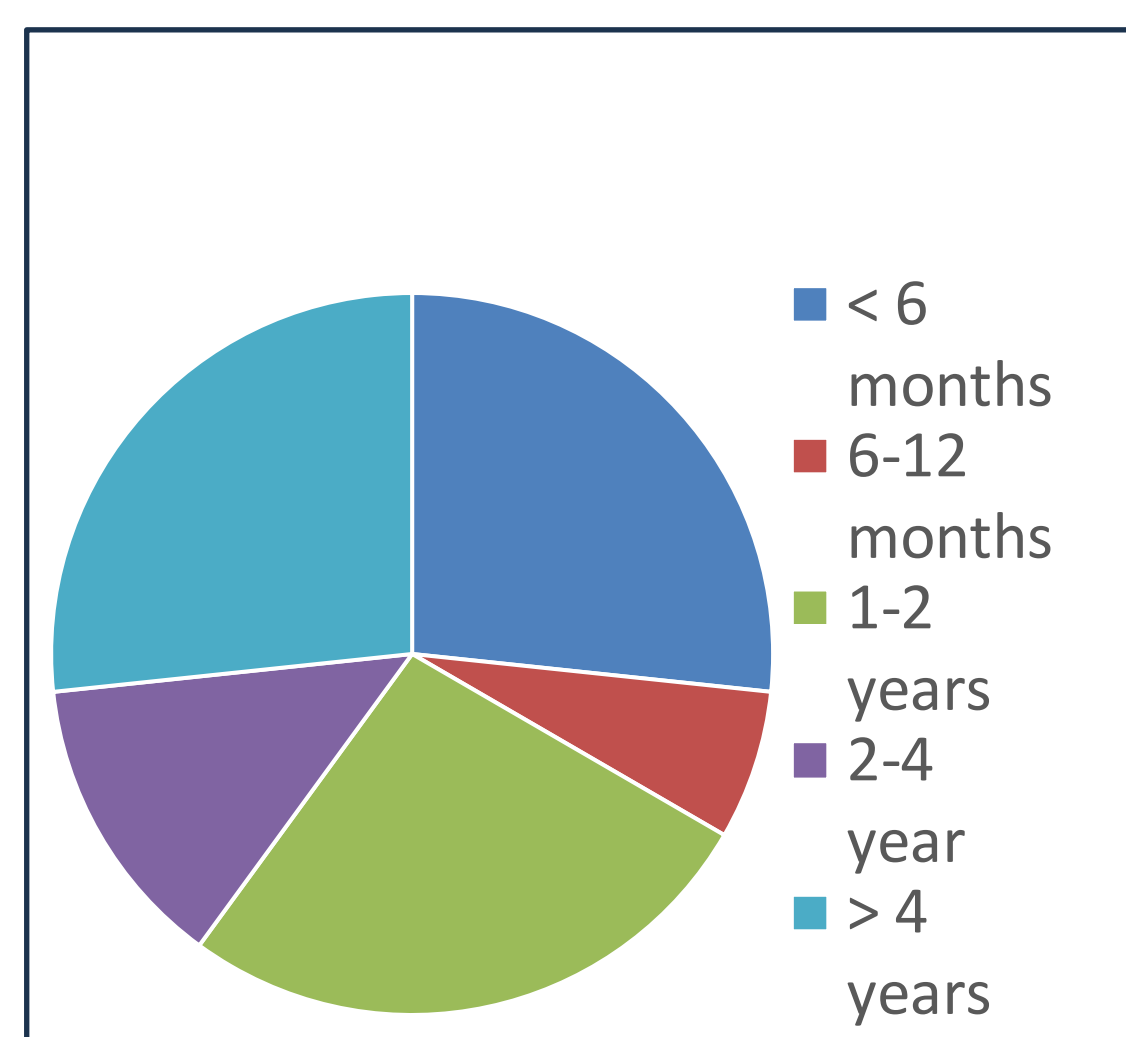
Relationship to OS:



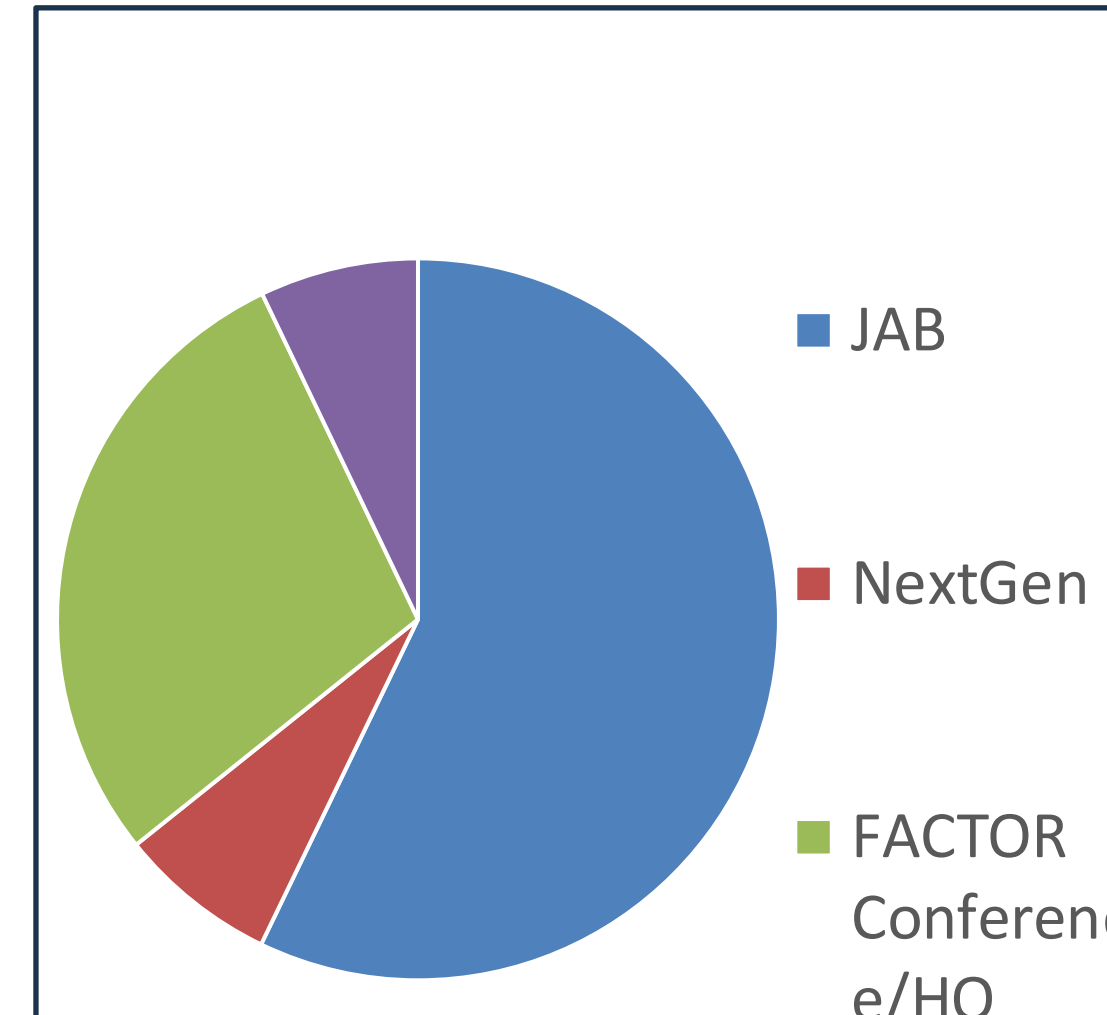
Board currently serving on:



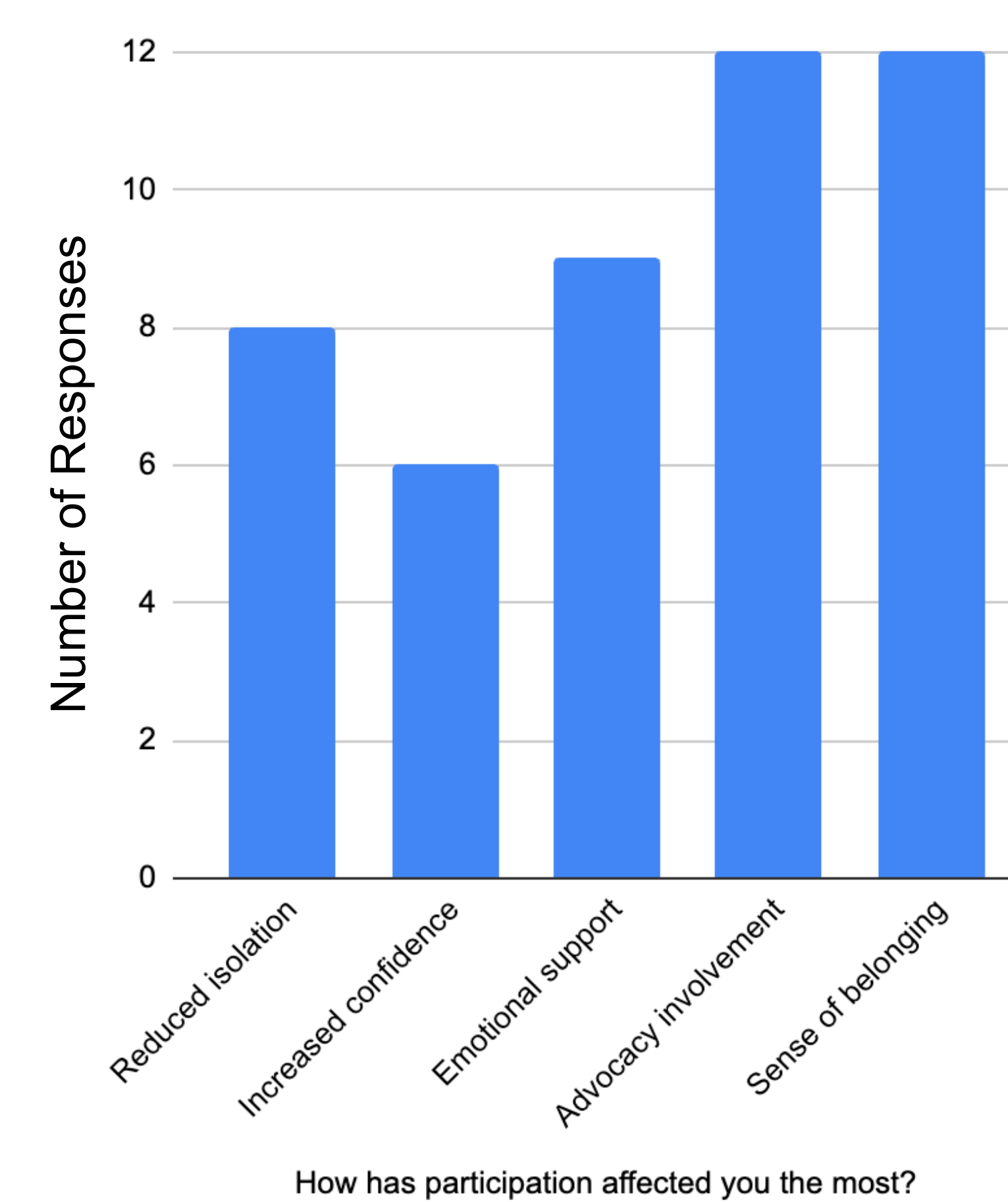
Time since joining MIB:



Program listed as most impactful:



How has participation affected you the most?

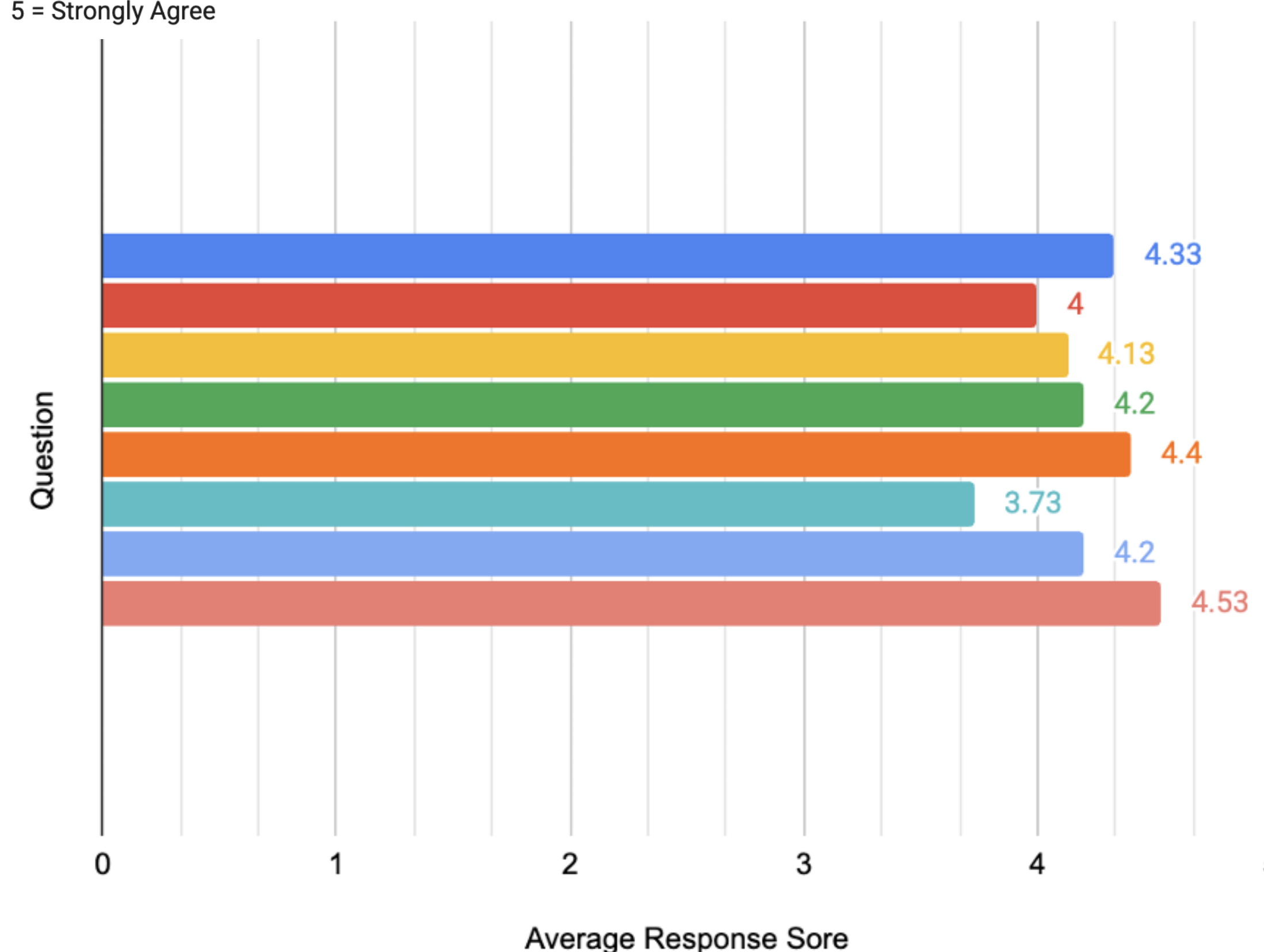


Survivorship Outcomes:

Participants were asked to rate how much they agreed to the following statements according to the following scale:

Use the scale below:
1 = Strongly Disagree
2 = Disagree
3 = Neutral
4 = Agree
5 = Strongly Agree

- | | |
|--|--|
| ■ I feel connected to others who have experienced osteosarcoma | ■ Participation in MIB helped me feel less alone |
| ■ I have built meaningful relationships through MIB programs | ■ I have developed new coping strategies through peer interaction |
| ■ I feel understood by peers in the osteosarcoma community | ■ Being part of MIB has helped me develop a stronger sense of identity |
| ■ I have someone I can talk to about my experience | ■ I feel that my voice matters in |



Discussion

Survey findings suggest that participation in MIB Agents programs is strongly associated with enhanced peer support and psychosocial well-being among those affected by OS represented on the 2026 JAB and NextGen cohort. Respondents reported high levels of connection (mean = 4.33) and feeling that their voice matters in the advocacy community (mean = 4.53). These results support the assertion that youth-led initiatives can address key gaps in survivorship, particularly regarding social isolation and lack of peer understanding.

Respondents consistently indicated that involvement in MIB programs reduced feelings of loneliness (mean = 4.4) and helped build meaningful relationships (mean = 4.0), suggesting the role of structured peer connection in coping with long-term mental obstacles associated with survivorship. Additionally, community-centered programs such as the JAB, NextGen, and FACTOR HQ were identified as the most impactful. Interestingly family members (primarily siblings) comprised 40% of the respondents and had similar responses to survivors across the board. It is important to recognize that siblings can face the same survivorship obstacles as OS survivors.

However, there was some variability in responses, particularly lower scores in coping strategy development (mean = 3.73). Additionally, differences in the duration of MIB involvement or level of engagement did not appear to significantly impact scores on the survivorship questionnaire.

Conclusion

Survey findings indicate that participation in MIB Agents programs is associated with strong peer connection, increased sense of belonging, and enhanced advocacy empowerment among individuals affected by osteosarcoma. High levels of reported connection and feeling heard suggest the role that youth-led, community-based initiatives play in addressing psychosocial challenges in survivorship. Additionally, participants noted reduced isolation and the development of meaningful relationships, underscoring the value of structured community engagement in coping with long-term mental obstacles associated with survivorship.

Although there was some variability in responses, particularly concerning coping strategy development, this highlights an opportunity for future improvement to better understand how programs can strengthen how these skills are cultivated among those affected by survivorship. While the sample size is limited (n = 16), these findings provide a foundation for exploring targeted strategies to enhance resilience in this population.

Overall, these findings underscore the importance of peer support as a component of osteosarcoma survivorship. Additionally, MIB Agents' community-based youth initiatives provide meaningful outlets to reduce isolation, strengthen identity, and empower young people within the survivorship community.

Acknowledgments

MIB Agents:
2026 Junior Advisory Board
2026 NextGen Cohort



AACR Scientist <-> Survivor Program

References

- (1) Marinoff AE et al. Clinical Targeted Next-Generation Panel Sequencing Reveals MYC Amplification Is a Poor Prognostic Factor in Osteosarcoma. JCO Precis Oncol 2023;7:e2200334 doi 10.1200/po.22.00334.
- (2) Leisenring W et al. Pediatric Cancer Survivorship Research: Experience of the Childhood Cancer Survivor Study. JCO 2009;27: e2319-2327 doi 10.1200

Contact

Email: max@mibagents.org

MIB Agents Website



MIB Agents Instagram

