

During our recent webinar, Victoria, an experienced registered nurse and parent advocate, shared key insights for advocating for a child with achondroplasia. Here, you can find the essential takeaways to keep in mind, along with some resources that she shared.



## Key Takeaways



### Be Prepared with Knowledge

Compile medical research ahead of appointments, creating a personalized resource like Victoria's 'Achon encyclopedia.'



### Meticulous Record-Keeping

Document all medical interactions and observations. Use journals, photos, and videos to track your child's condition.



### Streamline Health Records

Manage and update your child's health information with digital tools such as PicnicHealth, making it accessible for every healthcare encounter.



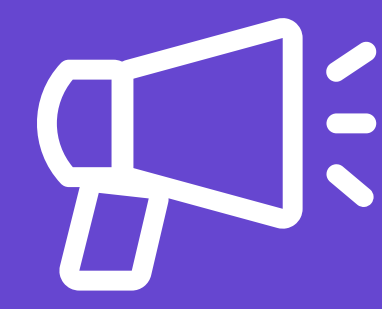
### Participate Actively in Care

Approach each doctor's visit with a prepared list of questions based on thorough research and everyday observations.



### Cultivate Community Connections

Engage with social networks and forums for support and access to studies and resources, like the VISTA study that Victoria found invaluable.



### Recognize Your Impact

Understand the critical role you play as your child's advocate, ensuring their voice is heard, and their care is optimal.

## Important Resources

- **International Consensus Statement for Achondroplasia**  
<https://www.nature.com/articles/s41574-021-00595-x>
- **AAP Health Supervision for people with Achondroplasia**  
<https://publications.aap.org/pediatrics/article/145/6/e20201010/76908/Health-Supervision-for-People-With-Achondroplasia>
- **ACH Growth Charts**  
<https://www.achondroplasia-growthcharts.com/>
- **Foaming and Bubbling around the mouth when the neck is in a flexed position**  
<https://onlinelibrary.wiley.com/doi/pdfdirect/10.1111/apa.15760>