

# Research and emerging treatment in bone dysplasia

Dear members,

There continues to be discussion in the media, the community and online about the Achondroplasia drug Vosoritide. The SSPA is acutely aware that personal views and opinions on treatments such as this are incredibly varied within the community, and we respect everyone's right to hold their view.

As an organisation, we believe our members and the wider short statured community deserve access to the most up-to-date and relevant medical information. Information is power, empowering individuals, parents and guardians to make informed decisions about their health and their children's health. The SSPA shares this information through the Professional Advisory Board, comprised of medical and allied health professionals with broad knowledge and expertise in skeletal dysplasia.

Our PAB is invited to share information about research and treatments with our members throughout the year and at the annual medical day, held at the SSPA convention each year. Furthermore, as part of the updated aims and objectives of the SSPA, it is important to us that we collaborate as equal partners with the medical and allied health professions for the betterment of all people of short stature and their families. Collaboration could take the shape of co-design of research projects. Or as mentioned above, ensuring all relevant information is made available about existing and emerging treatments. We know that every individual is different, but as lived experience experts, we can provide insight into an individual's experience if they choose a particular treatment or, similarly, if they decide not to receive a particular treatment. Especially for new parents. We would encourage all new research or treatment to include the contribution of lived experience from the beginning.

2023 is an exciting time for both research and treatment of skeletal dysplasia/dwarfism. This includes significant collaborative works such as the International guidelines for the treatment of Achondroplasia, research into pain and mobility as well as nutrition, and new thoughts on the timing and degree of surgeries and pharmaceutical treatments. With all this happening, this naturally leads to more choices for individuals and parents. These choices are highly personal and as an association we respect the individuals' right to choose treatment or not to choose treatment. Furthermore, that choice should not come with any judgement. Our community is small which makes it even more important that we support each other and welcome everyone with any of the now hundreds of conditions of dwarfism and their families. Working together, we can achieve equality of opportunity across all areas of life.

Regarding how these things are presented to the public, particularly through the media, the SSPA encourages everyone to come from a place of awareness and respect. Showing respect for adults living with these conditions, who live full and happy lives, respect for everyone's personal medical choices and respect for those with rare conditions that do not have the same treatments or research available to them. Sincerely,



Sam Millard  
National President - SSPA

