

Genetic Biotechnology Research Position Statement  
Little People of America Board of Directors  
July 2012

From its beginnings, Little People of America (LPA) has been deeply committed to the value of diversity within the human species. Our founder, Billy Barty, celebrated dwarfism as a valuable contribution to the diversity of the human condition and that tradition remains strong today, from the local to the national level. It is essential that we continue to value diversity, even within our own community and how our members respond to new genetic biotechnologies that seem to be on the verge of finding new treatments for dwarfism. We must recognize the importance of embracing difference within the membership of our own organization and support every family touched by the unique experience of dwarfism, especially as they grapple with these medical decisions.

LPA has always been an organization run by people with dwarfism to support others with dwarfism. This mission has historically included helping people with short stature and their families gain access to expert medical advice about the many complications of the various forms of dwarfism. The Medical Advisory Board has been a key ally in this aspect of our organizational mission and we look forward to maintaining and strengthening that link. On the other hand, LPA has never actively promoted medical research aimed at treating or curing dwarfism. While individual members have participated in research studies over the years, LPA has maintained that its organizational role is best understood as one of social support and advocacy. Even still, this does not mean that LPA is categorically opposed to all medical research, especially if it holds the potential to improve the quality of life of our members by treating symptoms that can range from uncomfortable to lethal. As medical science moves forward, we hope researchers will be mindful of our above mentioned commitment to the value of dwarfism as it contributes to human biological, social, and cultural diversity.

As part of our mission to support the community of people with dwarfism, LPA respects the choices of parents or individuals regarding medical intervention and hopes to continue to help provide access to accurate information to base these complicated decisions. We hope to help our membership better understand their rights as both patients and research participants, with the understanding that these are emotionally charged, complex, life altering decisions that sometimes come with both risks and benefits. Finally, LPA wants to reinforce our commitment to supporting all of our member's medical choices