



A Message From the President & CEO

Dear Parents and Family Members:

This is for you! Some time ago, a mother suggested that we put together a resource guide to address some of the issues you all face after giving birth to a baby with a limb difference or after your child has lost a limb due to trauma or a disease like cancer or diabetes.

Such incredibly difficult times are made worse by the lack of available information. Though perseverance and dedication to their child leads most parents to the information they need, it is almost always an uphill battle. We, therefore, hope that this guide will more conveniently provide the information you need if you are newly facing this situation or if you have lived with it for a while.

I lost part of my own leg in an accident when I was 6, and I can honestly say that I have had, and continue to have, a great life. I trained as a nurse, competed in many sports, married a wonderful man, and traveled the world working in Third World countries. I have been able to do all of this with ease because I have had the best of medical and prosthetic care.

Unfortunately, today, obtaining prosthetic limbs and services is becoming more difficult as insurance companies write policies that place unrealistic annual or lifetime caps on reimbursement or eliminate it altogether. Here, at the Amputee Coalition of America (ACA), we are working to reverse that trend, initially going state by state to introduce bills mandating appropriate reimbursement. This is especially important for young people with limb differences since they will likely need several prosthetic devices over their lifetime.

We will only be successful in these efforts, however, if we have the support of the entire limb loss community, including patients, providers and manufacturers, as well as the general public. To find out how you can help in this effort, call or e-mail Leslie Duncan at the ACA office (888/267-5669, lduncan@amputee-coalition.org). In the meantime, read the small print on your policy carefully, and never accept no for an answer. The "squeaky wheel" really does get the most attention!

We all hope that you find this publication helpful, and we welcome your suggestions for future editions.

Paddy Rossbach.

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Expectations

Parenting Children and
Teens With Limb Differences

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ACA Mission

To reach out to people with limb loss and to empower them through education, support and advocacy.

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