

***Little People of America***



# **IT'S A WHOLE NEW VIEW**

**A GUIDE  
FOR  
RAISING  
A CHILD  
WITH  
DWARFISM**

**By Joanna Campbell & Nina Dorren**  
A Publication of Little People of America, Inc.



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*Cover Photo: Courtesy of Gary Parker. Two teenage friends with achondroplasia.*

**T**his booklet is what we wish we were handed when we each learned about our daughters' dwarfism. Although the news of a child with dwarfism is almost always unexpected, we hope you too will come to see the difference as a wonderful gift, and a chance to learn about yourself and others. It has been a beautiful surprise that has given us a whole new colorful view of life and reaffirmed the importance of celebrating the differences in each of us.

We would like to thank our families, the LPA Board of Directors, the LPA Medical Advisory Board, and the family and friends of Amber Rose Jinks for their input and financial support for this project. We would also like to thank everyone who helped us refine this booklet, especially Ruth Ricker and Leroy Bankowski (LPA National Presidents), and John and Nancy Mayeux for their suggestions and encouragement.

*– Joanna Campbell and Nina Dorren, 1998*

**I**t's been 8 years since the first booklet was published and I'm thrilled to be able to share this updated version with you. My daughter is now 14 and we have gone through all of elementary school and middle school and let me tell you – it's been easier than I thought it would be – most days anyway. We've certainly had our fair share of negative comments, stares, and ignorant, rude people, but overall, we've found our world to be a pretty accepting and wonderful place. Of course, so much of our strength and ability to function well in a society that values "sameness" comes from important lessons we've learned from being part of LPA all these years. Our friends in LPA, our role models, our LPA family, are invaluable. I would like to thank Angela Van Etten, Ericka Okenfuss, Stacie Pouliot, Barbara Spiegel and Lois Lamb for their ongoing support of this project. I'd like to thank Louann McKay, Vicky Schulte and Patti Bell for their ongoing support of me personally as a friend and a mother. I would like to thank Rob Haines, the Orange Blossom Chapter and District 12 for being the greatest chapter and district an LPA member could ask for.

I would also like to thank my husband Jim for always being patient and supportive, my son Jack for finding the fun in any situation and for being such an incredible person with a big heart, and my daughter, Elizabeth, who I admire and love more each day. Your courage is inspiring and I'm proud you are my daughter.

*– Joanna Campbell, November 2006*

## **MISSION**

LPA is dedicated to improving the quality of life for people with dwarfism throughout their lives while celebrating with great pride Little People's contribution to social diversity. LPA strives to bring solutions and global awareness to the prominent issues affecting individuals of short stature and their families.



# **IT'S A WHOLE NEW VIEW**

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## TOPICS

1. Welcome to Holland
2. Definition of “Dwarf”
3. Genetics of Dwarfism
4. Feeling and Emotions of New Parents
5. What Exactly are my Child’s Differences?
6. Social Aspects and Common Concerns
  - 1) How do we tell our family and friends?
  - 2) When will people notice my child is little?
  - 3) Concerns about your child’s future
  - 4) Concerns about school.
7. Emotionally and Socially – Healthy Ideas
  - 1) Be aware of the myth that tallness=success
  - 2) Preparing your child for “being little”
  - 3) Avoid babying and overprotecting your child
  - 4) Relax and enjoy your child.
8. Safety
9. Medical Considerations
  - 1) What will the visit to the specialist be like?
  - 2) If we have a diagnosis, why should we continue to see a geneticist?
  - 3) Watch head size (head circumference)
  - 4) Low Muscle Tone
  - 5) Resting body temperature
  - 6) Nasal Passages
  - 7) Respiratory Concerns
  - 8) Ear Concerns
  - 9) Neurological tests
  - 10) Weight
  - 11) Cures
10. Practical Issues
  - 1) Practical Aids
  - 2) Clothes
  - 3) Toileting
  - 4) Books on Dwarfism
  - 5) Dwarfism groups on-line
  - 6) Financial help through government programs
  - 7) Adaptations in your home
11. Conclusion
12. “What I’ve Learned” by Joanna Campbell
13. School Letter Samples
14. Resources
15. Follow-up to Welcome to Holland
16. Medical Advisory Board

## WELCOME TO HOLLAND

**Y**ou may have learned recently that your child was born with a form of dwarfism. If so, the first thing to do, as hard as it may be, is to slow down and avoid jumping to conclusions. Before long you may begin to realize that having a child with a difference can bring you a whole new view. It will take a little time and lots of new information to start bringing this new picture into focus. The news that your child has dwarfism will lead you down paths you never thought you'd have to travel as a parent. But the journey can be very much worth the time, effort, strength and understanding you will develop. The very first step is to understand that the child you now hold in your arms may not be the baby you thought you'd have, but he or she is your baby and needs you now more than ever.

This general guide tries to address the most common questions and issues that new parents face. It highlights some major areas that you will need to gather more in-depth information on based on your child's specific form of dwarfism. This booklet is your guidebook to help you begin integrating some new views of life into a very personal perspective. Lots of information is given for new parents to start raising a child safely, with confidence and optimism. There is a wealth of support and help available should you desire it. It is wise to learn all you can.

The following brief essay may help you find a new perspective during those times when you may be feeling overwhelmed. It is reprinted with permission of the author.



Two friends both with Kneist Dysplasia.  
Photo Courtesy Gary Parker.

## WELCOME TO HOLLAND

*by Emily Perl Kingsley, 1987, all rights reserved*

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo, David. The gondolas of Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

“HOLLAND?!?” you say. “What do you mean, Holland? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”

But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay.

The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It’s just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It’s just a different place ... After you’ve been there for a while and you catch your breath, you look around ... and you begin to notice that Holland has windmills ... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say “Yes, that’s where I was supposed to go. That’s what I had planned.” And the pain of that will never, ever, ever go away ... because the loss of that dream is a very, very significant loss. But if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, very lovely things ... about Holland.

## INTRODUCTION

The topics that follow discuss different aspects of dwarfism. Since everyone perceives life through their own lenses, there are different perspectives and opinions on these issues. Hopefully, the information will help you ask your own questions, sort through the many answers you will receive, and integrate your own experiences and feelings into your own personal perspective. This personal perspective will color both your view of the world and your child’s.

## DEFINITION OF “DWARF”

**I**n general, “dwarf” simply refers to something that is much smaller than average. Technically, people who are 4’10” and under (and shorter than the norm for their ethnic background and family history), once they’ve attained their adult height, are considered short-statured, or a “dwarf” person. If the short-stature is caused by a genetic condition where it is the major characteristic, then it is probably a form of dwarfism. There are over 200 different forms of dwarfism. For this reason it is very important that you find out as much as possible about your child’s specific type of dwarfism. This booklet will provide some resources on how to go about this. In general, there are two classes of dwarfism - those who are in proportion compared to average-stature people and those who are not (i.e., who have “disproportionate short stature”). Proportionate dwarfism is generally related to hormone production. This accounts for



their small yet proportionate stature. Other medical conditions or simply having short parents may also cause proportionate short-stature. Persons with “disproportionate dwarfism” come in all shapes and sizes, short arms and legs with an average torso, shorter torso with longer arms and legs, etc. Most of these types of dwarfism are in the family of skeletal dysplasias. In the past, people with proportionate dwarfism were referred to as “midgets”, and people with disproportionate dwarfism were referred to as “dwarfs”. Midget is generally considered to be an old-fashioned slang term and is not considered correct or preferable by most in the dwarfism community.

A baby born with dwarfism occurs in 1 in 10,000 births. A baby born with achondroplasia occurs 1 in every 25,000 births, making achondroplasia the most common form of dwarfism. It is important for physicians to distinguish between achondroplasia and other forms of dwarfism. Every form of dwarfism has some medical complications associated with it. These range from mild to significant and vary in frequency, even within a specific type of dwarfism. Only a few rare types have an effect on intelligence. Because dwarfism in general is fairly rare, parents have to educate themselves and find appropriate medical care when needed. You will need to become your child's best advocate.

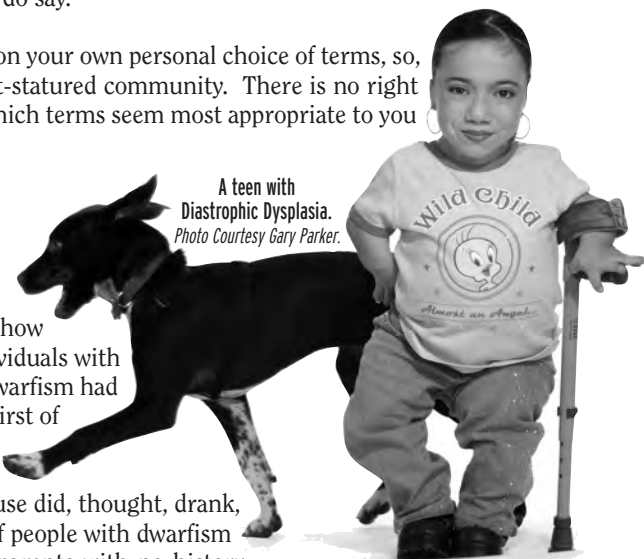
Most people, whether they have a skeletal dysplasia or are proportionately short, prefer the terms "short-stature," or "little person," or "dwarf". Although it may be a little hard for you to use the term “dwarf” at first, it is an acceptable term to most of the short-statured community. Some people prefer to be acknowledged as a "person with dwarfism." The difference is using “dwarf” as descriptive (as in “person with dwarfism”) vs. a defining and declarative statement (such as “He is a dwarf.”). It is also good to think about the use of the word “normal” – as in “normal height”. “Average” is the word most commonly used and preferred. For example; I am average-height. My daughter has achondroplasia. My son is average-height. Sometimes the words we don't say are as powerful as the words we do say.

Just as you will soon decide on your own personal choice of terms, so, too, have others in the short-statured community. There is no right or wrong answer. Choose which terms seem most appropriate to you and your family.

## GENETICS OF DWARFISM

**Y**ou may be wondering how two average-sized individuals with no known history of dwarfism had a child who has dwarfism. First of all, it is important to realize that dwarfism is not a result of anything you or your spouse did, thought, drank, ate or breathed. Over 80% of people with dwarfism are born to average-height parents with no history in the family. Make sure you talk with a qualified geneticist or genetic counselor and learn about your specific situation. The odds of having another child with dwarfism

A teen with  
Diastrophic Dysplasia.  
Photo Courtesy Gary Parker.





vary depending on the type of dwarfism. Some forms of dwarfism are recessive (carried within the parents' genes) and some are not. Achondroplasia, the most common form of dwarfism, is not recessive. It happens as a spontaneous mutation in the gene at conception. Parents of a child with achondroplasia, or other non-recessive type of dwarfism, have no greater chance of having an affected child in other pregnancies than they did with their affected child. Siblings of the child with dwarfism also do not "carry the gene". The child with dwarfism does carry the gene and the statistics for their children are as follows:

If a person with achondroplasia mates with a person with achondroplasia they have a 25% chance of having an average-height child, a 50% chance of having a child with achondroplasia, and a 25% chance of having a child who is double dominant. "Double dominant" means that the baby got a double-dose (one from each parent) of the achondroplasia gene. Unfortunately double dominant babies can not survive very long past birth.

- If a person with achondroplasia mates with an average-height person, they have a 50% chance of having a child with achondroplasia and a 50% chance of having an average-height child.
- As people with different types of dwarfism (dominant and recessive) mate the percentages change. For the most accurate numbers, please consult a qualified geneticist.

***A side note*** - much of the literature you will be read labels dwarfism in negative terms such as; disorder, disease, defective gene, abnormal, etc. Keep in mind that this is a very common medical perspective. Many people (the authors included) feel that being short-statured is perfectly normal (is it even possible to define "normal"?), just different from the majority of people.

## FEELINGS AND EMOTIONS OF NEW PARENTS

Depending on your personal life experiences, you may be feeling any number of a wide range of emotions now as you are adjusting to this new twist in your life. At first, many parents may feel numb, angry or sad. You may go through a period of shock and even deny to yourselves and others that the baby is little. Later, you may experience anger (at God, the Universe, or fate), a period of mourning or feelings of helplessness. You may also feel sad because the child you now have is different from the one you wanted and expected. It is important to talk about your feelings and work through your emotions during this period of adjustment. Your emotions likely will change as your knowledge grows.

Some parents do not experience these feelings of anger, disappointment, or sadness, or perhaps feel them only briefly. Perhaps they know some other little people already and by having a strong, positive point of reference, look at the situation differently. Some parents are delighted to have a short-statured child and perceive their child's difference as special and unique. If one or both of the parents are also short-statured this is especially likely. There is no right or wrong way to feel. One feeling is not better or worse than another. Allow yourself time to identify your emotions and come to terms



Photo courtesy Dan Verscha.

with them, whatever they may be. Many people find that contacting another parent of a child with dwarfism helps to answer questions, and then in turn, helps them to feel more confident and competent as a parent themselves. You may be asking yourselves “Can I do this? Can I parent a child who is physically so different from me, and from the majority of society?” The answer is YES, of course! Your child has a simple genetic mutation that is expressed in a very physical way – but the bottom line is – this is your child. Does it make parenting a bit harder? Yes. Will you have to contend with medical issues? Maybe. Is your child so potentially so different that you feel you can’t relate to them? We hope not. However, if this is a challenge that you would prefer to deal with in another way – i.e. give your baby up for adoption – LPA can help with that too.

As a support organization, Little People of America (LPA) has numerous people with many different forms of dwarfism available to talk with you if you are interested. Many parents of short-statured children have commented that they feel a family-like welcome and acceptance into the community of LPA. It is hard to feel alone with the support LPA members give each other. It is often helpful to talk with and be with others who share your particular difference. Also, you can benefit from other parents’ experiences in raising a short-statured child and the life experiences of adults with dwarfism. Information on how to contact LPA is listed in the Resource Section of this guidebook.

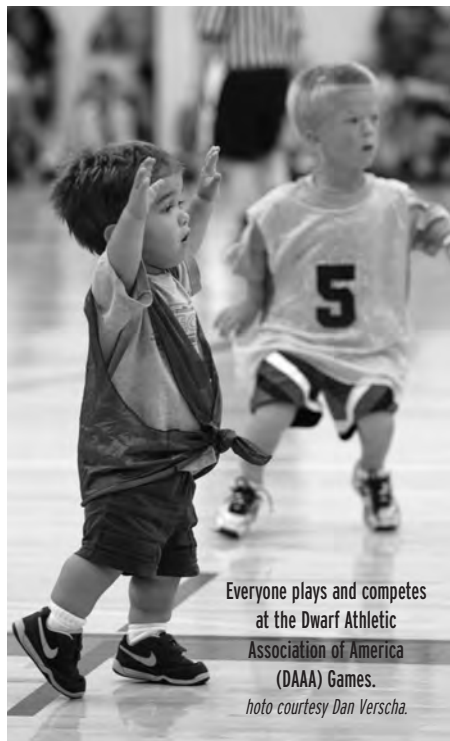
If, after full consideration, you decide to place your baby for adoption, please contact LPA. Our Adoption Coordinator keeps a list of families interested in adopting children with dwarfism. Some adopting families have average-height parents, other have adults with dwarfism. Hundreds of short-statured children from US and abroad have been adopted within the LPA community over the years. If you are worried that you might

not be the best choice as a parent since you are average-height, then you can calm those fears right now. If you are willing to learn, you will be the best parent, without a doubt, for your baby.

## WHAT EXACTLY ARE MY CHILD'S DIFFERENCES?

**Y**our short-statured child is physically different from average-statured children, especially in the case of a skeletal dysplasia. There may be some noticeable mechanical differences between the bodies of an average-statured child and a short-statured child. These differences vary according to the type of dwarfism your child has. It is important that you discuss this topic early on with someone who is very familiar with your child's form of dwarfism. We recommend seeking advice from the doctors on LPA Medical Advisory Board, listed in the back of this book or on-line at [www.lpaonline.org](http://www.lpaonline.org). This is because the child's schedule of development will be different from average-statured infants. You can obtain growth and development charts for some forms of dwarfism. Not only do infants/children who have dwarfism accomplish certain milestones (i.e., sitting, crawling, walking, etc.) at their own pace, they often do it in their own unique way. It can be very harmful to your child if you push them to keep on the "standard" schedule of development. For example, in children with achondroplasia, safely sitting alone unsupported may not happen until around one year old, and walking alone may take up to two years. This is perfectly normal for a child with achondroplasia and knowing it may set a parent's mind at ease.

Over time, you will discover other unique physical differences relating to smallness.



Everyone plays and competes  
at the Dwarf Athletic  
Association of America  
(DAAA) Games.

*photo courtesy Dan Verscha.*

For example, you may find that your child perspires a lot and that the body gets warmer faster than that of an average-statured infant. The resting body temperature may be higher than the expected 98.6 and breathing may be faster. Obviously, certain brands of clothing may fit better than others. Children with dwarfism may have more earaches or colds.

In the area of intelligence, people with dwarfism are almost always no different from average-statured people. Unless your situation is very rare and is coupled with some sort of complication, your child's intelligence and other mental capacities will not be affected.

Socially and emotionally, every child, including your short-statured child, grows in direct response to how they are accepted and treated. In this area your personal perspective of dwarfism is extremely important. Your child has the

same social potential in this area as any person. Sometimes there seems to be a social difference because we (the parents, friends, relatives, professionals, society) focus on the physical difference. One thing to keep in mind is that your child is a child first, not a “problem” (medical or otherwise) or a cross to bear, or a result of “bad genes.”

If a child receives love, learns that “normal” is a matter of perspective and that their difference is unique and special, then a positive outlook likely will result. This child may have better social skills, emotional strength and self esteem, which has been developed from successfully coping with the physical and social challenges of being different in today’s society. Fortunately, society is more accepting of differences now than years ago. On the other hand, a child who feels unloved, “abnormal,” or freakish may not have the self-esteem needed to meet the challenges of being different in our society. In such a case, a negative outlook may develop in this child, resulting in poor social skills and overall unhappiness.

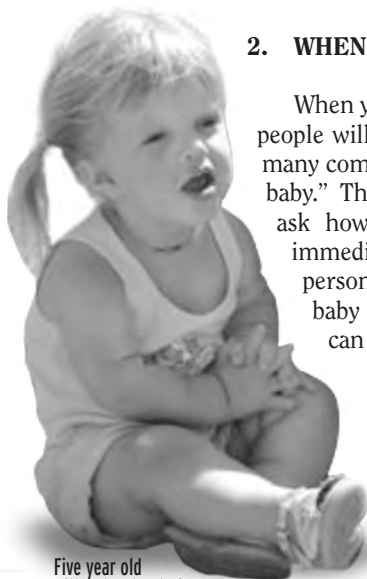
Raising any child with a difference in our society can be extremely challenging. Fortunately, as the parents of a short-statured child, you have lots of support and knowledge available to you. The next section, on social and emotional issues, may answer many of your questions.

## **SOCIAL ASPECTS AND COMMON CONCERNS**

### **1. HOW DO WE TELL OUR FAMILY AND FRIENDS?**

As difficult as it is in the beginning, you need to be aware that your attitude will color your social interactions and others’ opinions regarding your child. Put some thought into how you will tell others about your child. If you are devastated, they will be devastated, too. We are not suggesting you hide your feelings. But be aware that months down the road when you have adjusted, they will still remember how devastated you were at the time and may not let you forget it. However you explain it to your friends and family is how they will begin to adjust to the news themselves. You will be put in the role of educator, and sometimes you will end up comforting others. Some people may ask lots of questions, others may shrug and say “Oh, O.K.”. The most frustrating thing of all may be that you never know which response to expect. You will hear all kinds of statements and some may make you angry. Try to keep in mind that people are not trying to be mean; they just may lack tact. Some people will surprise you and be wonderful. Most importantly, make sure you have a “safe place” to express your feelings, even the ones you may not want to admit. Whether it be with your spouse, parent, sibling, counselor or friend, give yourself permission and time to come to grips with this new information. It’s one of the most important things you can do for your child and your future.

Being different in our society can be very difficult and frustrating. It is not always hard, though. Sometimes it can be rewarding to be unique and have lots of attention. Being different is special. There is no denying, though, that discrimination is widespread in our society and even the most positive attitudes can have rainy days when everything seems to dampen the spirit. This is a good time to call another parent of a short-statured child. Just knowing and talking to someone who understands what you are going through, who can laugh with you through the tears, can bring back a positive attitude.



Five year old  
with achondroplasia.

## 2. WHEN WILL PEOPLE NOTICE MY CHILD IS LITTLE?

When your child is very young (the first few months) many people will not even notice a difference. You may receive as many comments that you have a “big baby” as you do a “small baby.” Then, you will begin to notice a pattern; a stranger will ask how old the baby is, you will answer, and almost immediately you may see the imaginary wheels inside the person's head begin to turn, trying to figure out “If the baby is supposed to be 8 months, why is she so little?” It can be rather amusing.

With casual acquaintances or strangers, remember it is up to you what and how much to say. Some days you may feel like talking, and the person may be especially receptive. Other days you will just want to get your grocery shopping done as quickly as possible because company is coming over and the house is a mess. It will vary each day, maybe even each hour. You do not have to

educate “the world”, just your child's world (family, friends, schools). As your child gets older and is walking and talking, but stays small more people will notice and perhaps ask you about your child's difference. However, by then you will have experienced all types of situations and it will just be life as usual. Other parents can be a great resource at this time as to what simple wording they've developed to explain the difference. Keep in mind, the general public is not very educated about dwarfism, and the concept of dwarfism comes with many assumptions thanks to mythology and Hollywood. In general, the more simple your explanation, the better.

Other people's interest in your child can be an opening to educate others on your child's difference and to dispel some ignorance or false beliefs. Most people are very receptive and interested to hear what you have to say. Also, keep in mind that human beings are by nature prone to notice and learn about differences. This accounts for many of the stares and finger pointing you may encounter over the years. People see a difference that they don't recognize or don't know much about, and before they even realize it they may be staring or pointing. They usually do not intend to be rude or insensitive; it is just part of being human. Being emotional is human too, so don't be surprised if one day you're only too happy to have the opportunity to talk about your child and the next day the same questions or actions drive you crazy.

You will find over time that you can become very concise and adept at explaining to people about your child's difference. Some parents even print up a brief, informational paragraph to hand out to interested persons for those times when they don't have time to stay and talk. It is recommended to be aware of how your child sees you react to points and stares. As hard as it is sometimes, your reaction in front of your child should be positive, kind, and calm, if possible. Children learn by observation. Your child will develop their own way of handling these situations.

Your role is to guide your child to growing into a happy, healthy adult, not to create someone who is mad at the world.

### **3. CONCERNS ABOUT YOUR CHILD'S FUTURE**

Perhaps you may be concerned with what your child will be like as an adult. Little people do virtually everything average-statured people do. They grow up and live independently of their parents. They get married, have children, go to college, work in any number of careers. They drive cars, fly airplanes, ride horses, participate in sports, etc. Every year many in the short-statured community and their average-statured families attend a National Conference. LPA organizes the week-long meeting in a different city each year. New parents can benefit tremendously by attending, especially if you are in an area with a small LPA Chapter or in an area where there are no current LPA Chapter meetings or events. There are special workshops for new parents, as well as many social activities. This can truly help allay any concerns, because you will meet many successful people of short-stature and see a positive future for your child: students, lawyers, teachers, business persons, accountants, ministers, artists, musicians, mothers, fathers, engineers, journalists, authors, nurses, doctors, and secretaries. As your child grows up, the Conferences can be an important part of your child's identity. She or he will find role-models and friends for life. As children begin to understand they are little (around ages 4-5), and will always be little, a friend with dwarfism or role model can help tremendously as they integrate the information into their personality. Knowing and seeing others will help your child handle the dwarfism, and alleviate a feeling of aloneness. When you, as a parent, can look your child in the eye and say "I know you are going to have a great future. I know you are a wonderful person. Yes, things may be hard sometimes, but I know in my heart that you have a great life ahead of you", then you will know that everything will be OK and that together you and your child will weather the rough patches and be just fine.

### **4. CONCERNS ABOUT SCHOOL**

A common question parents ask is whether or not their child needs to attend a "special" school. The answer is emphatically "no." As to public vs. private, you should make that decision as you would for any other child. Each type of school has its merits. Luckily, if you are new parents, you will have quite a while before you face that decision. Whichever school you choose for your child, be prepared to educate the staff and administration about your child before school starts. This education should be done in daycare and preschools as well. Most schools are very cooperative in adapting the environment so that your child can maintain his or her independence and not be unduly physically stressed. It is a good idea to have Individualized Educational Plan (IEP) or "504 Plan" on file with your school. An IEP or 504 can help guarantee your child's educational success and comfort and safety in the classroom. The Resource Director (or Special Education Professional - the terms vary from state to state) for your school or district will be able to tell you more. A few well-placed stools are generally all that is necessary in the early years. The extent of the adaptation is up to you and the school. Be aware that there are certain legal avenues that you can use to require adaptations in the school if the administration is less than cooperative. These include Section 504 of the Rehabilitation Act and the Individuals with Disabilities Education Act. There is a



good chance that your school has never worked with a little person before. Keep in mind that you must be partners in your child's education and be willing to help the school get to know your child and his or her own special needs. You are your child's best advocate. Most children with dwarfism fall under the "orthopedically concerned" area. That designation should be able to let the school apply for funding for any particular equipment, if necessary.

Other common questions concern how a short-statured child will handle their height with classmates. Before your child starts their first day of school, plan a brief informational session with the teacher and principal so they learn how to answer questions in line with your terminology and philosophy. "The Family Corner," a newsletter published in the 1990's for parents by LPA members, which is now on LPA's Website ([www.lpaonline.org](http://www.lpaonline.org)), has some excellent examples of letters for school staff and other kids' parents. There is also a sample letter in the back of this booklet. Some local charitable foundations, such as the Shriners, offer a puppet show called "The Kids on the Block" with has some puppets with dwarfism. They are often available to do presentations to classes or schools. There is a videotape, "What Children Want to Know About Little People," available through LPA designed for presentations to grade-school children. Also an LPA member may be willing to come and speak to your child's class or school. (Check with your child first.) It will be up to you and your child how far to take the education. What happens in any given classroom is the same phenomenon that happens in the world at large. Initially, your child may be singled out and noticed for being different. After a brief adjustment period, your child should be just fine. Like any difference, once the person is better known, the difference takes second place to personality and making friends.

## EMOTIONALLY AND SOCIALLY - HEALTHY IDEAS

### 1. BE AWARE OF THE MYTH THAT "TALLNESS = SUCCESS"

"Many people have traditionally associated "bigness" with power. In primitive times a large person had an advantage in fighting or hunting. Now, however,

Teen boys - just being typical teens

*Photo Courtesy Gary Parker.*





strength of character, intelligence and personality have replaced strength of body, force and size as necessary ingredients for success. Society still tends to overvalue tallness and physical prowess, but you as a parent can emphasize to your child and others that what really counts is the child's personal qualities." (*John Rogers and Joan Weiss, LPA Medical Advisory Board, 1979.*)

## **2. PREPARING YOUR CHILD FOR "BEING LITTLE"**

Your child's awareness of being little will probably happen around ages 4 - 6. There is usually no one particular point in time when your child realizes that they are little. It is a gradual process of recognition. The timing of self-awareness may depend on your involvement with other little people and LPA. You can help this develop in a healthy way by utilizing the following suggestions:

- a. Place mirrors low enough on the wall so the child frequently sees him/herself.
- b. Provide opportunities for your child to associate with other little people. It is important that your child have friends of both short-stature and average-stature.
- c. Consider joining a group such as LPA and attend local chapter, regional district meetings or national conferences.
- d. Answer your child's questions about him/herself with sensitive, simple, age-appropriate answers.

Make sure you have discussed this topic with your child and have helped them come up with a simple explanation before other people begin asking questions of them. Practice the responses with your child so that they will be comfortable when he or she has to do it alone.

Many little people grow up without knowing any other dwarfs and progress through life just fine. These ideas are meant as suggestions. Some are more important than others at various times in your child's life. When your child is very young and does not know he or she is little, support groups are generally of more benefit to the parents. But just because your child is young, don't overlook this important opportunity. Don't downplay the idea of a "support group". Look at it as a chance to make some friends and have fun. Other parents offer a wealth of information and friendship. The exposure is also good for siblings. As for your child's benefits, it may be easier to "grow up in LPA" and to have always known people with dwarfism than to be suddenly thrust into the short-stature community at age 10, 14 or 23. For a parent's perspective on what she's gained by being involved with LPA since her child was young, read the article "What I've Learned..." in the back of this booklet.

## **3. AVOID BABYING AND OVER-PROTECTING YOUR CHILD**

Treat your child according to age, rather than size, and encourage others to do the same. Let your child walk, even though it may be easier and faster to carry them. Encourage independence in dressing and toileting at age-appropriate times. Consider rearranging bowls, glasses, etc., to a low cabinet in the kitchen so that your child can help themselves and share in chores, or at least place stools in

necessary places. Lower the microwave. If possible, lower the light switches. Dress your child in age-appropriate clothes. This may mean more alterations, but your child's self-esteem is worth it. Discipline your child with dwarfism the same way you discipline your other children. Encourage your child as you would your other children to try new activities. Children will learn to trust themselves when they see that you trust them.

#### **4. RELAX AND ENJOY YOUR CHILD**

### **SAFETY**

**S**ome safety issues are specific to each form of dwarfism. Again, seek the advice of a qualified specialist or knowledgeable individual for your specific situation. Always start with, or encourage your local doctor to contact, the doctors on the LPA Medical Advisory Board (MAB). Also, talk with other parents of a child with a similar form of dwarfism who can relate their experiences and answer your questions. Regardless of the specific form of dwarfism a short-statured child is built differently than others with whom you are familiar. You may need to make some adjustments to keep your child safe and healthy, while he or she is an infant and toddler. Here are some issues that need to be considered. (More health issues are discussed under the next section titled "Medical Considerations.")

1. There is clear evidence that SIDS (sudden infant death syndrome) is far less likely in babies who are placed on their back for sleep. That remains appropriate for most infants with dwarfing processes. However, some (such as those with achondroplasia) have a very prominent back of the head and, if placed on their back, will force their head into flexion (bent forward). And that can be a problem for breathing. If when you place your infant 'back to sleep' the head is forced forward so the chin touches or approaches the chest, then using a neck roll – a tightly rolled towel or washcloth behind the neck – might be a good idea. Some babies who have severe reflux and spitting up may do better sleeping on their sides. Side-lying will decrease risk of choking for these babies.
2. As the child gets older and more mobile, it is all right to let them position themselves in the most comfortable way. Older infants with achondroplasia (6 months and up) may choose to sleep on their back with their neck extended and face to the side. Generally they do this to better open their airway. Don't worry. Although it looks uncomfortable, this is normal and adaptive since it helps them breathe more easily.
3. Extra support for the head and neck is very important for nearly all babies with dwarfism, especially if their head size is large and/or their neck muscles are weak.

Keep the upper back, neck, and head in a safe, stable position when holding your baby or transitioning them from one position to another. In car seats and strollers make sure the head is well supported and can't bounce from side to side. Make sure the head does not fall into a chin-on-chest position by the baby being placed too far upright, since this can make it difficult for the infant to breathe. It may take some creativity to pad the child's car seat or stroller to achieve the best position.

4. Extra back support is often needed. It may take quite awhile for the child to build up enough muscle strength to support their body weight. The child's back may start to curve if allowed to be in unsupported positions often. A safe bet may be to keep the floor very clean and let this be your child's domain. Let your child play on their stomach and back much of the time and let them achieve milestones such as rolling, crawling, sitting, and walking when their muscles and back are sufficiently developed and at their own pace.
8. Avoid any form of the Johnny-Jump-Ups or doorway bouncers. The combination of sudden movement and lack of head control could result in serious injury.
9. Learn about your child's expected schedule of growth and development based on the particular type of dwarfism. It will both ease your mind and alert you to possible problems to have a realistic timetable.



A couple and their daughter. The mother has achondroplasia, the father has Cartilage Hair Hypoplasia, their daughter is average-height. *Photo Courtesy Gary Parker.*

10. Avoid doing any physical therapy exercises to improve head control, muscle tone, or catch upon gross motor delays unless you (and your doctor and physical therapist) have consulted a specialist in your child's form of dwarfism. What many people label as gross motor delay in your child often will simply be a different schedule of development. Physical therapy will not change the fact that your child's body mechanics are different from an average-statured child. It isn't at all clear whether physical therapy is or is not generally beneficial to children with dwarfism. Some children, however, will have special problems or concerns that should be addressed through such therapy

11. Be aware that the top half of your child's body may be relatively heavier than the bottom half and their center of gravity relatively high. Take precautions so that the child does not fall out of things such as swings or strollers. It may mean adding a shoulder strap in some places. Be especially careful with shopping carts.

# Little People of America



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A one year old with  
Metaphyseal  
Chondrodysplasia

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Young boy with  
Pseudoachondroplasia

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Six year old girl with  
Achondroplasia

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**Teen baseball player with Achondroplasia at a DAAA event.**

Photo Courtesy Dan Verscha

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**Basketball player at DAA event.**

Photo Courtesy Dan Verscha

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**Baseball player with Hypochondroplasia.**

Photo Courtesy Dan Verscha

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# Little People of America



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A father and daughter, both with Spondyloepiphyseal Dysplasia Congenita (SEDC).

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A family at the National Conference, mother and son both have Osteogenesis Imperfecta (OI), and father has Achondroplasia

Photo Courtesy Dan Verscha

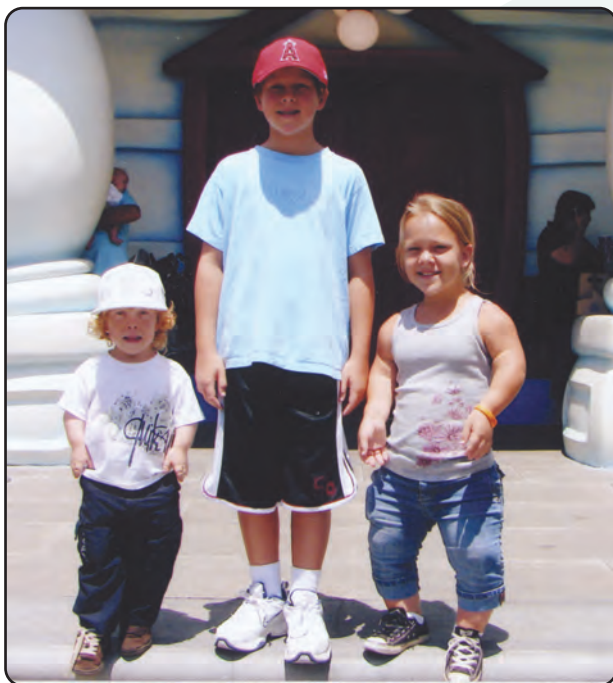
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One of the benefits of LPA is creating life long friends. These pictures were taken in 1997 and 2006, respectively. The girl has Achondroplasia, and is with her average height brother. The boy has Acromesomelic Dysplasia.



12. Sometimes when a child with dwarfism begins to walk they topple over and fall easily, usually face forward and sometimes face first. Although it looks awkward, children do learn to cushion the blow by pushing out their chest and rolling slightly forward if their arms are too short to get in front of them to take the force of the fall. Give your baby a safe environment, free from obstacles like tables and chairs so that they can learn to control their body without getting hurt.

As you read through this section on safety it may seem like a lot of things to think about and to do or not do. Many of the points listed, though, are common sense things people do for very young average-statured infants, too. The key is that many of these practices need to continue much longer for a dwarf child.

Enjoy watching your child grow and develop in their unique way. The adaptations children come up with are wonderfully creative and workable.

## MEDICAL CONSIDERATIONS

**S**pecific medical considerations vary greatly depending on the form of dwarfism involved. A correct diagnosis is very important. A series of x-rays may be taken to confirm the diagnosis, possibly even genetic tests to differentiate very similar types of dwarfism.

When your child is seen by specialists, they will determine if the baby is having any sort of trouble or complication which needs to be taken care of right away. If there are no problems, then the geneticist will just probably ask to see you again in the near future, usually every 6 months or once a year. Be sure and ask for any growth and development charts that are applicable to your child's dwarfism, and any other medical literature they may have so that you can begin to educate your child's pediatrician. Your pediatrician will provide the standard routine care, such as immunizations, well-baby checks, and all of the standard childhood illnesses. If your pediatrician does not seem willing to learn about your child, consider finding a new pediatrician.

Your local physician may have experience with dwarfism, but most do not, so it will be up to you to share contacts and information with your doctor. There are several physicians in the United States who specialize in dwarfism. You or your doctor should contact them if you have questions or concerns. Many of them participate on the LPA Medical Advisory Board and are listed in the Resources Section of this booklet. If your child is having serious problems, it may be best to have an appointment with one of the dwarfism specialists or have your local specialist consult with them by telephone, fax, etc. Also, often specialists affiliated with LPA donate their time and patients can be seen free-of-charge at LPA Regional and National Conventions.

Short-statured individuals have some general medical considerations in common. These areas may or may not develop into problems for your child. They are listed here for your information, and as topics to raise with the specialists who care for your child.

1. What will the visit to a specialist be like? A visit to the specialist is similar to a well-baby check. Specialists may ask you questions about eat, sleep and play patterns, movement, temperament. They will take measurements of the baby. They may suggest certain tests to be performed or x-rays taken. A geneticist will explain your chances of having another child with dwarfism. It is common to feel confused and overwhelmed during and after the first visit to the specialist. You may not understand some of the medical terminology or other issues being explained. Do not hesitate to ask any questions. It may be useful if someone else is with you to take notes and remember questions you wanted to ask. Most specialists are helpful and do not mind answering questions that may arise later. Start a file or folder of information on your child. It should include doctors' reports, insurance information, general dwarfism information, well-baby checks, immunization records, allergies to medication. If your child is hospitalized or needs surgery, you will want to have all of this pertinent information in an easy-to-reach place.
2. If my child is healthy and we have a diagnosis, why should we continue to see a geneticist or other specialist familiar with dwarfism? The best reason to continue to see a specialist periodically throughout childhood is simply



Dr. Pauli, Chair of the LPA Medical Advisory Board and a patient visit at a National Conference.

experience and the ability to give you expert guidance in anticipation of the next stages of development. Your pediatrician may be perfectly capable and willing to learn, which is wonderful. But the bottom line is he or she will not have the same degree of experience in dwarfism. It is very reassuring and comforting to be able to go to a specialist who does not have to look your child up in a medical textbook. A geneticist or specialist should be able to identify any potential problems much earlier than a pediatrician. It is not uncommon for a child to have cervical spine instability which is an extremely critical problem for many diagnoses (SED, pseudo, Morquio, etc.). Depending on your child's type of dwarfism it is highly recommended that you continue with an orthopedist, geneticist, or a neurologist for regular follow-up visits to make sure a correctable problem is not developing without being noticed.

3. Watch head size (head circumference.) A marked increase in head size could indicate hydrocephalus. This is a treatable complication that sometimes occurs when fluid is trapped in the head if the opening at the base of the skull is too small to allow proper circulation. Be aware that, in achondroplasia, the front (anterior) part of the head will appear to grow outward at about 3-6 months. This is to be expected. Just keep an eye on it. Very few dwarf children actually need to be treated for hydrocephalus. Any diagnosis of hydrocephalus should be considered very carefully. It is fairly common for hydrocephalus to be misdiagnosed with children with achondroplasia. Be sure you are seeking the best medical care with doctors who are knowledgeable about your child's type of dwarfism. It is always wise to seek a second opinion if you are in doubt, and especially if surgery is indicated.
4. Low muscle tone is normal for many forms of dwarfism. See the section on "Safety" if you have questions. The bottom line is - do not force your child to do anything his or her body does not seem ready to do, even if "everyone else's baby" is doing it. Forcing a child to sit up before the back, neck and stomach muscles are ready can cause damage. Sometimes a bump will appear in the middle of the child's back, called kyphosis, which may need bracing to correct.
5. Be aware that your child's resting body temperature may be higher than 98.6. Due to a smaller chest cavity, they may have a faster rate of breathing as well. This often means kicking off all covers at night, sweating when they sleep, and tiring easily when walking or running. It is essential to make sure your child drinks plenty of fluids, especially in warm weather or when playing very hard.
6. Nasal passages may be smaller in your child. Your child may seem to have a constantly stuffy nose. If so, discuss this with your doctor before you give any sort of over-the-counter decongestants or medicines. In some forms of dwarfism, achondroplasia especially, children have a depressed nasal bridge. This can contribute to the snoring and heavy breathing, particularly at night.
7. Respiratory concerns - There are different reasons a child may experience respiratory complications such as apnea (cessation of breathing). There are two types of apnea: central and obstructive. Central (neurological) apnea occurs when there is pressure on the spinal cord in the foramen magnum area due to a small foramen magnum opening. Obstructive apnea occurs due to the

smaller nasal passages and throat area and/or enlarged adenoids and tonsils. This can account for prominent snoring. Also, due to the small size of certain bones, the chest cavity may be smaller as well, which can affect breathing. Any presence of apnea should be considered serious and medical attention should be sought. A sleep study, a common test, may be ordered to determine which type of apnea exists.

8. Due to the smaller size of the middle part of the face, many children with dwarfism have problems with fluid in the middle ear, ear infections and varying hearing loss. If the child is not hearing well, there may be delays in speech and language development. Even mild, off and on hearing loss can affect learning in the classroom. This area should be monitored closely by your physician and school nurse. Many children, both average-statured and short-statured, have tubes put in to keep the middle ear healthy and free of fluid.
9. Does your child need any neurological tests or a baseline MRI (magnetic resonance imaging)? Future neurological problems may be indicated on an MRI; and it can act as a baseline for future comparisons. Consult with your doctor on the necessity of this test.
10. Watch weight gain. Because children with dwarfism grow slowly, an overweight child could easily grow up to be an overweight adult. A healthy diet and exercise are very important for your child. However, the extra rolls of skin and fat common in infants frequently decrease once they are mobile toddlers. A plump infant with dwarfism is "normal" and is probably not in need of any type of food restrictions - just careful food choices. As with all children, let the child regulate his food intake as much as possible. A child with dwarfism should not be eating as much as his average-size siblings or friends. Let your child be your guide. Portion sizes are one of the few things that should be based on size rather than age for LPs.
11. **"Cures"** - This can be a very controversial topic. Many people with dwarfism feel that there is nothing "wrong" with being little and therefore there is nothing to "cure." Other people, though, would rather be more similar to average-statured individuals in height and appearance. At this time there are no "cures" for most types of dwarfism; the exception being some kinds of pituitary dwarfism where a person lacking certain hormones can be given medication. Also, recently exact genetic mutations (changes) have been located for achondroplasia and a number of other types of dwarfism. This opens up the possibilities for treatments in the distant future. At this time limb-lengthening is the only option that changes height for several types of disproportionate dwarfism. Limb-lengthening involves breaking the bones of the legs and/or arms, and inserting a metal rod with pins that is turned millimeters every day. The process can take years to complete and is very expensive (\$80,000.00 to \$120,000.00) and painful. Limb-lengthening is still considered experimental and may or may not be covered by insurance. There are many complications to be considered, including nerve damage and infection. Participants report varying degrees of pain associated with the procedure. An orthopedic surgeon who has experience in limb-lengthening can tell you more. Most LPA members do not choose to undergo this procedure, however, recognizing it is

a part of our community, LPA promotes the following recommendations; 1). that limb-lengthening only be done at multi-disciplinary medical centers which offer a counseling component and have familiarity with dwarfism, 2). that it not be done before puberty. It is important that the child be fully aware and mature enough to consider all the implications of the life-changing decision he or she is making.



## PRACTICAL ISSUES

The best way to learn about some of the practical issues of being little is to contact other little people or the parents of a little person (see Resource Section). The following are some general subjects about which you may have questions.

### 1. PRACTICAL AIDS

There is no need to re-invent the wheel. The following items/ideas are available in many varieties; light switch extenders, the ability to add a lower lightswitch on the wall, door knob extenders, stools, potty chairs, adaptive furniture including desks and chairs, temporary or permanent pedal extensions for driving cars, etc. Of course, your child won't need these things for a couple years or more but at least you know they are available. For more information check out LPA's website and pages on Helpful Products.



## **2. CLOTHES**

While your child is an infant, finding clothes that fit usually isn't a problem. Just shop where you usually do and ignore sizes. Look instead for cuts and styles that fit. As your child gets older, finding age-appropriate clothing and styles may be more difficult. Choose carefully, and you should be fine. You may choose to alter clothes or even sew them yourself. There are some specialty stores that tailor-make clothes, as well as a computer program that generates individualized patterns, but these generally are for teens and adults. Often at LPA gatherings, such as the national conference, there are clothing swap tables. You will probably find a brand or two that works particularly well.

## **3. TOILETING**

When your child is old enough for potty training, be adaptable. You will face some unique challenges. Initially a potty chair may be easier to use than the regular toilet. Most toilets will come up to your child's waist or mid-back and it takes some creativity to maneuver out of one's clothes and up onto the toilet. Little boys can urinate into a container and dump it. Your child may use a step stool to climb up and sit on the larger toilet. Those with short arms may use adaptations or adaptive devices to make it easier to maneuver pants down and up, and for wiping. Other possible challenges depend on your child's form of dwarfism. Fortunately, this is a topic which everyone has to deal with. There is a wealth of information through LPA such as in The Family Corner section on LPA's Website or the Parents of Little People 2 (POLP2) group on yahoo.groups online.

## **4. BOOKS ON DWARFISM**

Most public libraries have very few, if any, books or listings on human dwarfism. Medical libraries do have information on dwarfism, but it is clinical and probably won't be of much help or comfort to a new family. There are, however, several good books and booklets available. See the Resource Section and contact LPA for a list of books and how to obtain them. Many books and resources can be found on Amazon.com and at [www.lpaonline.org](http://www.lpaonline.org).

## **5. DWARFISM LISTS ON LINE**

Through the internet, and LPA local and national newsletters you can be put in touch with other parents of little people or adults of short-stature. On-line [www.lpaonline.org](http://www.lpaonline.org) can link you to the various lists that members and friends have created.

## **6. FINANCIAL HELP THROUGH GOVERNMENT PROGRAMS**

Even though you may not consider dwarfism a disability, many laws do. Some forms of dwarfism also have secondary complications that qualify for disability aid. Even if you are uncomfortable with the term "disabled", it is smart to know what resources may be available to you. Don't get hung up on the word

“disabled”- or you may miss out some valuable programs offered in your area, like physical therapy or adaptive pre-school. This aid includes many areas, such as equal opportunity laws, college grants and loans, parking placards, supplemental security income (SSI), and early intervention programs. Some of the benefits of these programs include funding for medical care, funding for adaptive equipment, and help in implementing laws which require public schools to provide necessary adaptations so that your child can successfully attend school (IEP). Some, but not all, are available to all families regardless of income. Contact your local department of Social Services, hospital, or grade school Resources Support/Special Education Professional for more information.

## 7. ADAPTATIONS IN YOUR HOME

As your child grows older you will find you naturally make adaptations along the way, such as stools and extenders. There are differing views on how much major restructuring should be done in the home. Some people "scale down to size" the child's bedroom or bathroom for comfort's sake but the rest of the house is up for debate. One view is that the child should be as comfortable as possible in their own home and therefore many adaptations are made. Another view is that the child lives in an average-height world, which includes the rest of the family, and therefore few structural changes are made. The major guideline is making adaptations so the child can be as independent as possible.



A young married couple, both with  
achondroplasia.  
*Photo Courtesy Gary Parker.*

## CONCLUSION

**T**his guide book has lots of information for you and your family which will require time to digest. It may be helpful to re-read it as the shock wears off and you get more accustomed to the idea of difference in your child and in your life. We hope that from this booklet you will gain the confidence that you need, and have the basic knowledge with which to begin the journey of raising your child.

Remember that "normal" is a matter of perspective. Trust in yourself and your personal view, even if it differs from someone else's. Enjoy your baby or child and his or her uniqueness. In their own way, they will bring to you a whole new beautiful view of life and all of its wonder and possibilities.

# **“WHAT I’VE LEARNED”**

*By Joanna Campbell*

*(I wrote this for my last newsletter as President of the Orange Blossom Chapter (Orange County, CA) of LPA. At the time, my daughter was 13). April 2006*

First and foremost, the time has come for those of us that re-started the OBC to pass the LPA-OBC baton to new families. When Vicky Schulte and I re-started OBC more than 10 years ago, her daughter Michelle was just beginning kindergarten and my daughter Elizabeth was 2\_. Michelle is now looking at colleges and Elizabeth is firmly involved in the middle-school/pre-teen world. I remember, at the beginning, I couldn’t even think about her going to kindergarten! My baby! How would she do? Turning her loose in the big world! No Way!

Well, both girls have grown up beautifully and I know a huge part of that is due to our involvement with LPA, both locally and nationally. I have learned so much from my friends in LPA; average and lp, adult and kids. Here are a few of the things I’ve learned.

I have learned how to have grace when you really want to rip some strangers head off because they are being rude.

I have learned how to tell the difference between innocent curiosity and a person who is a jerk.

I have learned to have patience when it takes longer to get places.

I have learned to focus on my children, husband and friends like there is no one else around when we are in public – because no one else matters anyway.

I have learned that sometimes it really stinks when the water park won’t let you on the slide you’ve done 12 times before, but that the management will also give in (one time) when your whole class is chanting “Let her go!” behind him.

I have learned to shop carefully for clothes and shoes.

Through my adult lp friends I have learned when something is really an issue and when to let something go, and most importantly, when I was being foolish or overprotective or too sensitive.

I learned to have a thicker skin – that’s probably one of the biggest lessons.

I’ve learned that, for the most part, the world is a good place, but that once in a while, some comment, or accusation, or assumption will come out of the blue and take your breath away.

I've learned that sometimes seemingly healthy people will end up with surgery no matter what.

I've learned to be an advocate for my children which has carried over into being an advocate for my life and other family members as well.

I've learned not to be intimidated by doctors.

I've learned it's not a question of "having" the time, it's a question of "making" the time. Everyone's life is busy, but we make time for our priorities.

Personally, I've learned what some of my skills are; how to put on a Regional and National Conference, how to organize an event, and how to run with an idea and make it happen.

I've learned to laugh and be proud of who each of us are.

I have learned that believing with every fiber of my being that my children will have a great life makes all the difference.

My wish for everyone who comes in contact with LPA – whether it be average-height parents or an lp child – is to find just one friend. OBC re-started because Vicky and I became friends. We started as women who had something in common (daughters with dwarfism), but then we became friends and created a relationship on our own.

## SCHOOL LETTERS

*(A note to parents considering school letters: There seem to be two schools of thought on school letters. One is "My child would be mortified if I sent a letter out about her!" The other is "The more I can educate the people around my child the better, so the weight of "fitting in and explanation" does not fall entirely on her shoulders." We have personally found that kids new kids primarily have 4 or 5 basic questions they want answered about the child's difference, and then everyone seems to move on, but with a new level of understanding. Don't confuse quietness with acceptance or understanding on the public's part. The decision to use a school letter or not is purely individual and should be made after consideration of your environment and your child's personality.)*

September 7, 2000

To: The Staff at Main Street Elementary School

This week our daughter, Elizabeth, began second grade at Main Street in Mrs. Smith's class. Elizabeth has a form of dwarfism called achondroplasia, and there are a few things we thought may be helpful to pass on to you about her. We've enclosed the letter for the Main Street parents with the basic information for your review, but as teachers, we would like to give you some more detailed information relating to Elizabeth and her safety.

1. Please advise the other children, as necessary, that Elizabeth is the same age as other first graders (she will be 8 this month) and that she is not a "baby". Being called a "baby" is the one thing that can really irritate her.

Please remember, and remind others, to treat her as any other 8 year old child in your classroom, or the school.

2. Please let Elizabeth do as many things on her own as possible. We are encouraging her to be independent. This may mean finding a creative way to do something, or that a task takes a little longer for her to complete. Usually it involves standing on a chair or stool. Elizabeth has very good balance and will generally tell you when she can't reach something, or feels unsafe.
3. Please do not let other children pick up or carry Elizabeth. Although tempting during play, a hard fall can be very serious for her.
4. Elizabeth will often feel warm to the touch, and is usually comfortable in cooler weather.
5. Because her arms and legs are short Elizabeth tends to fall more than other children, usually on her stomach. Although it looks painful, she rarely gets hurt unless it's a fall from a height or she hits her head. She usually just pops right back up and continues on with whatever she was doing.
6. One of the things that bothers Elizabeth is to be in the middle of a large group of kids, when she feels she may be hurt or not seen. She may feel more comfortable if you are able to encourage her to be near a teacher or special friend, where she may feel safer in a large group.
7. Games that involve running like Tag and Duck/Duck/Goose can be very frustrating for her. Although I want her to participate fully in the classroom and in P.E. I don't want her to dread games like these. Perhaps for now it is best to follow Elizabeth's lead as to her comfort level of participation.
8. Elizabeth's spine and neck are more susceptible to trauma than other kids so activities that put a strain on her neck, or any type of whiplash motion are to be avoided. She is not to do a somersault, although she can do a cartwheel. She will be instructed to stay off of the monkey bars and high climbing structures.

Elizabeth can be quite strong-willed and funny. We sincerely hope you will enjoy having her in your class and at Tustin. We certainly enjoy having her in our lives. If you have any questions, please do not hesitate to contact us. We'd also like to thank Mrs. French and her custodial staff for making Elizabeth's physical environment more comfortable. You don't know how much that means to her, and to us. Thank you!

Sincerely,

Jim and Joanna Campbell

September 12, 2001

To: Grade 1 - 3 Parents, Main Street Elementary School

Many of you received this letter last year, but with the increased growth of Main Street, we thought it would be a good idea to pass this out again.

Our daughter, Elizabeth, is attending second grade this year at Main Street. We are writing this letter because Elizabeth has achondroplasia, a form of dwarfism, and we have found it is quite common for both children and adults to have questions about her condition. Even though your child may be older or younger than Elizabeth, they may meet on the playground or at another school event. Friends have found it helpful to have a little information. The following are a few basic facts about dwarfism:

- There are over 200 distinct types of dwarfism. Elizabeth has achondroplasia which is a bone growth disorder that affects the long bones of the arms and legs.
- Some dwarfism types are recessive (carried within the parents' genes), others are what are called "spontaneous mutations at conception". Elizabeth's form is not recessive.
- There are no "cures" for Elizabeth's type of dwarfism, although limb-lengthening has been used on some people. Limb-lengthening is a controversial and painful procedure, which happens during puberty. HGH (human growth hormone) does not work for Achondroplasia.
- Over 80% of all people with dwarfism have average-height parents and siblings, as is our case.
- Elizabeth's adult height will be some where around 4' 2", about the height of an average-height first or second grader.
- It is extremely rare to have retardation in conjunction with dwarfism; only a few very rare types correlate to any type of mentally handicapping condition.

*Terminology:* the word "midget" is not used anymore among most in the short-stature community; it is seen as a derogatory, slang word. We use the terms "short-stature", "little person" or "having dwarfism" in our home. The word "dwarf" is technically correct although we rarely use it when speaking about a person.

We also use "average-height" as opposed to "normal-height". Everyone has their own opinions, but to us, people with dwarfism are just shaped differently, not "abnormal". Elizabeth has a 4 year old average-height brother.

Elizabeth knows she is a little person and is pretty good at explaining it when asked. She usually says "My bones don't grow as fast as yours, and that makes me short", or something to that effect. If you are asked by your children why she is short, that may be a good way to explain it to them.



The reason this letter is being sent is to help stop any teasing that may occur. We are looking forward to this year at Main Street and have been extremely pleased with the openness and cooperation we have received from Mrs. French and the Main Street staff. If you have any questions please do not hesitate to contact us.

Sincerely,  
Jim and Joanna Campbell

## ORGANIZATIONS INFORMATION RESOURCES

### 1. **Little People of America**

1-888-LPA-2001

<http://www.lpaonline.org>

The LPA website has the most comprehensive collection of organizations and information on dwarfism. LPA has a complete database of resources and other organization online.



A mom and her son with Spondylo-epiphyseal Dysplasia (SED).

## OTHER RESOURCES

### 1. **Little People of America's Medical Resource Center.**

<http://medical.lpaonline.org/>

The LPA Medical Resource Center (MRC) is the official site for medical information about dwarfism (conditions of short stature), sponsored by the Little People of America, Inc. (LPA).

The MRC is a project whose mission is to provide public access to the latest and most accurate medical information available about dwarfism and its associated conditions. All information published within this domain has been reviewed and approved by LPA's Medical Resource Director. The Medical Resource Director works in conjunction with the LPA Medical Advisory Board in choosing and developing the content for this site.

### 2. **LPA Today** - national newsletter. A benefit of membership.

### 3. **Midwest Regional Bone Dysplasia Clinic**

Offers a variety of pamphlets for a nominal charge. See address for Dr. Richard Pauli in the Medical Advisory Board Section

### 4. **Dwarf Athletic Association of America (DAAA)**

Organizes sports events throughout the United States.  
[www.DAAA.org](http://www.DAAA.org)

## **CELEBRATING HOLLAND - I'M HOME**

*By Cathy Anthony*

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned. I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger, the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

*Cathy Anthony is a parent, advocate and presently the executive director of the Family Support Institute in Vancouver.*

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*\*Honorary life members*



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