

# SOCIAL, EMOTIONAL AND SPIRITUAL WELLBEING OF CHILDREN WITH VITILIGO

---

ALANNA F. BREE, M.D.



BE THE  
CHANGE  
YOU WISH  
TO SEE IN THE  
WORLD

I AM HONORED TO BE HERE AND I AM THANKFUL FOR  
THE OPPORTUNITY TO SHARE THIS TIME WITH YOU



# Unique privilege of being one of 326 board certified pediatric dermatologists in the US

- Provide care for infants, children, adolescents and teens
  - Diagnosis and management of skin, hair and nail conditions
- Many common conditions that can be treated successfully
- Many rare conditions that may not have a cure
- Opportunity to address the physical needs of my patients is a large part of my job



# A Children's HOUSE For Pediatric Dermatology

Our mission is to provide exceptional pediatric dermatology care and an extraordinary patient experience that consistently exceeds expectations.







# What I really love about my job



The opportunity to address the social, emotional and spiritual aspects of skin conditions and birthmarks



Our mission is to encourage and unite children and their families who are affected by skin disease and birthmarks by providing opportunities for social, emotional and spiritual support.

# The significant need for social, emotional and spiritual support

- Study of the health-related quality of life for children with chronic skin conditions compared to other chronic diseases of childhood (diabetes, epilepsy, asthma, kidney disease and cystic fibrosis)
  - Chronic skin disease ranked second to cerebral palsy in regards to impairment of quality of life
    - Profound effect on the psychosocial development
- Two out of five children with a chronic skin condition have some psychosocial impairment
  - social withdrawal
  - lack of confidence
  - depression
- This is not surprising, considering Americans spend more on their appearance than on health and education combined.
- Our society is one that values external beauty and esteems conformity with aesthetic standards which unfortunately leads to social stigma, alienation and bullying of individuals affected by skin disease.
- As a result, these affected children commonly internalize the consistent negative reactions from others and often suffer from a lifetime of poor body image and low self-esteem.



# Vitiligo can be more than skin deep

- Millions of people worldwide have vitiligo
- Affects up to 1-2% of the population
  - Males and females are equally affected
  - Occurs fairly equally in all skin types and all races
- Half of those affected will develop it before the age of 21
- It is typically a persistent condition but there are treatments available
  - Variable effectiveness, especially in some areas of the skin
  - Recurrences can be common after repigmentation
- It is not life-threatening but it can be life-altering
  - Significantly more likely to have depression and anxiety
  - Reported to negatively impact quality of life in many studies
    - Especially in younger patients and if there is involvement of the hands

**SO HOW DO WE REWRITE THE  
STORY FOR OUR CHILDREN  
AFFECTED BY VITILIGO?**

---

**FORTUNATELY YOUR CHILDREN  
LOOK TO YOU FOR GUIDANCE**

---

**YOU HAVE THE OPPORTUNITY  
TO CO-AUTHOR THEIR STORY**



**FIRST YOU HAVE TO ACCEPT  
THAT THEY HAVE VITILIGO**

---

**IF YOU CAN'T ACCEPT IT YOURSELF  
THEY WILL STRUGGLE TO DO SO TOO**

**YOUR OPINION OF YOUR CHILD  
SHOULD BE ABOVE ALL OTHERS**

---

**YOU HELP TO SET THE BAR OF HOW  
OTHERS WILL SEE AND TREAT YOUR CHILD**

**ANXIETY IN PARENTS =  
ANXIETY IN THE CHILD**

---

**RESEARCH SHOWS THIS IS THE #1 INDICATOR**



**EMPOWER THEM WITH  
UNDERSTANDING  
& KNOWLEDGE**

---

**THEY ARE AFFECTED BY VITILIGO  
BUT NOT DEFINED BY IT**

**DON'T BE AFRAID TO DISCUSS VITILIGO  
AND HOW YOUR CHILD FEELS ABOUT IT**

---

**IT IS OBVIOUS TO THEM TOO  
WHEN YOU AVOID HEALTHY DIALOUGE  
IT LEADS TO SHAME AND WITHDRAWL**

**YOU DO NOT NEED ALL OF THE  
ANSWERS TO START A  
CONVERSATION WITH YOUR CHILD**

---

**ADMIT THAT YOU DON'T KNOW AND  
BE WILLING TO SEEK THE ANSWERS TOGETHER**



**ANSWER THE QUESTIONS  
YOUR CHILD ASKS**

---

**NOT THE QUESTIONS YOU THINK THEY HAVE**

# CONVERSTATION STARTERS

- I know that you have been seeing some changes in the colors of your skin.
- Do you have any questions about that?
- Do you want to know more about your skin?

# WAYS TO SHARE INFORMATION

- There are 3 things I wanted to tell you about your skin:
  - 1) I wanted you to know that even though you are noticing some changes in the color of your skin, you and your skin are still very healthy. Except for having trouble protecting you from sunburns, your skin can do all the jobs it needs to do.
  - 2) If you have any questions, you can ask me or the doctor anything.
  - 3) No matter what, I love you so so so much. I think you are beautiful and wonderful. I wouldn't change anything about you.

# VITILIGO THROUGH THE AGES

---

PSYCHOSOCIAL DEVELOPMENTAL  
CONSIDERATIONS

# PRESCHOOL (3-5 YEAR OLDS)

- Intellectually concrete thinkers: Things are either good or bad – so they need to hear from adults around them that their skin is “good” or “ok” even if it looks different.
- Socially: Gaining personal independence so this is a perfect stage to help them learn the word vitiligo. Then they can tell other people who might ask, “My skin is healthy. It just has vitiligo so it is changing color.”

# SCHOOL AGE (7-12 YEARS OLD)

- Entering into logical thinking stage. Might be interested in learning about the “why” behind vitiligo. Or might just need to hear: its nothing you or anybody else did “wrong” and there was nothing you did to “catch it”; its just something that happens sometimes. Just like some eyes can’t see very well and they need glasses to see better.
- Can teach simple concepts like: The body is made up of little tiny building blocks called cells. Skin has some cells that give it color. For some reason, right now some of your skin cells that make your skin color are not working. Its like they are on vacation. We might be able to bring them back from vacation with medicine or the light machine or they might stay away for awhile. We will have to see.
- Socially for older school-agers: This is the age when they start to compare themselves to others. They move from saying things like “ I am a really good dancer” to “I am the very best dancer in my class.” So in this stage, we need to expect they might start comparing their skin to others. This is a great stage to introduce them to camp and other activities where they can see other types of skin conditions. Pointing out other differences in classmates can be helpful too. It can help kids to realize differences are really common: friends with glasses, friends with allergies, friends who use a wheelchair, friends who have lots of freckles, wear braces- all of these are different types of differences. Some you can; see some you can’t, but we actually all have something different about us.



# TEENAGER (13-18 YEARS OLD)

- Can think abstractly: “Why me? Why would God do this to me?” Socially: Their identity often rests in what they feel their peers think about them. In this stage, they are dealing with the personal fable “That would NEVER happen to me” OR “That always happens to me and only me” and an invisible audience “Everyone is always looking at me and watching me.” So this age and stage can be tricky.
- Foster relationships with positive older mentors who aren’t parents but that parents really trust. Continue to foster peer relationships through camps and support groups. Introduce positive coping skills and don’t try to diminish or hide emotions but focus on expressing them appropriately.
- Allow make-up if they want or support them in going without it. Let them take the lead in these decisions and be supportive of their decisions. Ask questions and let them tell you what they need from you. Of course you are the parents! So sometimes you have to tell, but if you can, ask! “What way could I help you the most when you feel upset?” or “Do you like it best when I come and ask you what is wrong or do you want me to wait until you come to me?”

# SKIN CHANGES ARE OBVIOUS TO OTHERS

---

SO DEALING WITH OTHER PEOPLE'S REACTIONS  
AND RESPONSES ARE PART OF THE JOURNEY

# ENCOURAGE YOUR CHILD NOT TO HIDE

---

IT ONLY MAKES THE GAP BETWEEN YOU AND OTHERS WIDER  
IT BECOMES A SECRET THAT CAN'T BE ADDRESSED

**HELP YOUR CHILDREN SEE  
THAT THEY WERE MADE TO  
STAND OUT FOR A REASON**

---

**THEY MAY BE NOTICED BECAUSE OF THEIR VITILIGO BUT  
LET THEM FIND A POSITIVE PURPOSE TO BE RECOGNIZED  
AND KNOWN FOR INSTEAD OF THEIR VITILIGO**



**WE ARE EACH UNIQUE MASTERPIECES**

---

**EMBRACE WHO YOU ARE**

**WHEN YOU TRULY LOVE  
AND ACCEPT YOURSELF**

---

**YOU WILL FIND THAT OTHERS LOVE  
AND ACCEPT YOU TOO**



**BEAUTY IS MUCH MORE  
THAN SKIN DEEP**

---

**LET YOUR TRUE BEAUTY  
SHINE OUT FROM THE INSIDE**

**YOUR CHILDREN ARE WATCHING WHAT YOU  
DO AND LISTENING TO WHAT YOU SAY**

---

**SO PLEASE BE A POSITIVE EXAMPLE**

# **GIVE GRACE TO YOURSELF AND GIVE GRACE TO OTHERS**

---

**EVEN IF IT SEEMS LIKE THEY DON'T DESERVE IT  
WE ALL HAVE CHALLENGES**

# PEOPLE WHO STARE AND ASK QUESTIONS ARE TYPICALLY JUST CURIOUS

---

MODEL HOW YOUR CHILD SHOULD RESPOND

TAKE A DEEP BREATH & LOOK AT IT AS A GOLDEN OPPORTUNITY

PRACTICE A RESPONSE TOGETHER

HAVE VITILIGO AWARENESS BUSINESS CARDS

**BE YOUR OWN BEST ADVOCATE**

---

**BUT PLEASE DO IT WITH KINDNESS AND RESPECT**

# **FOLLOW THE GOLDEN RULE**

---

**TREAT OTHERS HOW YOU WANT TO BE TREATED  
AND THEY OFTEN FOLLOW YOUR LEAD**



**DO NOT ALLOW THE ACTIONS OR  
WORDS OF OTHERS TO DICTATE HOW  
YOU FEEL ABOUT YOURSELF**

---

**THEY DO NOT HAVE POWER OVER YOU  
UNLESS YOU GIVE IT TO THEM**

# **STRUGGLES ARE UNAVOIDABLE**

---

**ALLOW YOUR CHILDREN TO BE INDEPENDENT  
SO THEY CAN LEARN TO BE RESILIENT**

**SOMETIMES YOU JUST  
NEED TO LISTEN**

---

**YOU DO NOT ALWAYS NEED TO HAVE  
AN ANSWER OR TRY TO FIX IT**

# VALIDATE THEIR FEELINGS

---

ALLOW THEM SPACE TO FEEL WHAT THEY ARE FEELING

DON'T TRY TO EXPLAIN AWAY THEIR EMOTIONS

# **BE THERE TO SUPPORT YOUR CHILD**

---

**BUT SOMETIMES THEY NEED TO BE ABLE  
TO FIGURE THINGS OUT ON THEIR OWN  
SO RESPECT THEIR NEED FOR BOUNDARIES**

**HELP THEM FIND ACTIVITIES AND  
HOBBIES WHERE THEY CAN SHINE**

---

**THIS HELPS BUILD SELF-ESTEEM AND IS A  
COPING TOOL FOR DEALING WITH THEIR FEELINGS**

# COPING ACTIVITIES

- It is okay to be upset or angry at times
- Ways to deal with those feelings:
  - Exercise
  - Taking deep breaths
  - Doing art
  - Listening to music
  - Journaling
  - Hanging out with friends

**ALLOW YOUR CHILD TO PARTICIPATE  
IN TREATMENT DECISIONS**

---

**DO NOT MAKE THE TREATMENT  
WORSE THAN THE PROBLEM**



# DEVELOP A GOOD SUPPORT NETWORK

---

LOOK TO OTHERS WHO HAVE GONE BEFORE YOU  
DON'T BE AFRAID TO ASK FOR HELP

**KNOWING YOU ARE NOT  
ALONE IS POWERFUL**

---

**WE ARE STRONGER WHEN WE COME TOGETHER**

# REMAIN CONNECTED WITH YOUR LOCAL VITILIGO SUPPORT GROUP

---

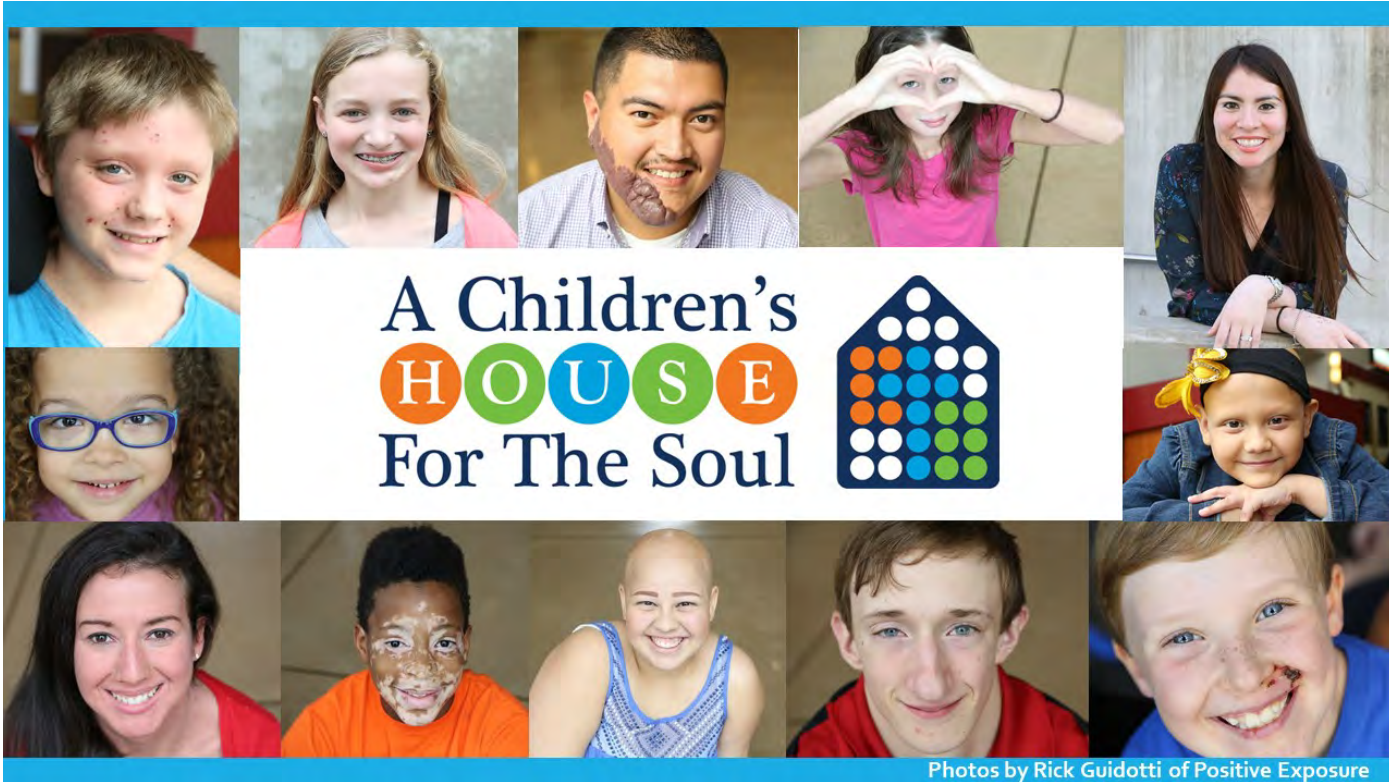
IT IS IMPORTANT FOR YOUR CHILD  
TO SEE OTHERS WHO ARE LIKE THEM



# SEND YOUR CHILD TO THE AAD'S CAMP DISCOVERY

---

THEY LEARN SO MANY VALUABLE LESSONS



CONNECT  
WITH A  
CHILDREN'S  
HOUSE FOR  
THE SOUL

---

SO WE CAN HELP YOUR CHILD  
LOVE THE SKIN THEY ARE IN

# FOCUS ON YOUR FAITH

---

TRUST THAT GOD HAS A GOOD AND  
PERFECT PLAN FOR YOUR CHILD'S LIFE

WORRY DOES NOT EMPTY

TOMORROW OF ITS

SORROW, IT EMPTIES

TODAY OF ITS STRENGTH.

**CORRIE TEN BOOM**

**WORRY  
LESS**

---

“Never be  
afraid to  
trust an  
unknown  
future  
to a known  
God.”

Corrie ten Boom

10 June 2013 9:27 am

PRAY  
MORE

---



# LEO NI LEO



Let your light shine before others, that they may see  
your good deeds and glorify your Father in heaven.  
Matthew 5:16

©cemius.com

**Live abundantly the unique life that was created just  
for you and use your special gifts to help bless others!**