



DARBY BOINGEE
LEARNS THAT

EVERY FACE HAS



A SPECIAL SMILE!

WRITTEN &
CREATED BY
MICHELLE
BAIN

**PROACTIVE
PARENTS/GUARDIANS
GUIDE**

DESTINATION: SMILE!

HI, PARENT/GUARDIAN!

IF YOUR CHILD WAS BORN WITH A CLEFT LIP OR PALATE, LIFE CAN BE FULL OF CHALLENGES. WE MADE THE BOOK *DARBY BOINGS LEARNS THAT EVERY FACE HAS A SPECIAL SMILE!* FOR CHILDREN BORN WITH CLEFT LIP, CLEFT PALATE OR CRANIOFACIAL ABNORMALITIES. THIS BOOKLET WILL HELP YOU GET A BETTER SENSE OF THOSE CONDITIONS AND LEARN HOW TO READY YOUR CHILD FOR HIS OR HER OWN SPECIAL JOURNEY.



The world is made up of different faces with different smiles. Help your child see that the world is a better place with his or her special smile in it!

DISCLAIMER: This book provides general information about cleft palate and craniofacial deformities. This information is not intended to be used for the diagnosis or treatment of cleft palate or craniofacial deformities or as a substitute for consulting a licensed health professional. Consult with a qualified physician or health care practitioner to discuss specific individual health needs and to professionally address cleft palate, craniofacial deformities or other medical concerns.

WHAT IS CLEFT LIP/CLEFT PALATE?

By Definition

CLEFT: SPLIT, DIVIDED OR PARTLY DIVIDED IN TWO.

THE BOOK *DARBY BOINGS LEARNS THAT EVERY FACE HAS A SPECIAL SMILE!* TELLS THE STORY OF FELICITY, A GIRL BORN WITH A CLEFT LIP AND PALATE.

By Definition

PALATE (PAL-IT): THE ROOF OF THE MOUTH.



BABIES BORN WITH A SPLIT IN THEIR UPPER LIP HAVE CLEFT LIP. THOSE BORN WITH AN OPENING IN THEIR PALATE HAVE CLEFT PALATE. SOME BABIES ARE BORN WITH BOTH, LIKE FELICITY.

THESE OPENINGS OR SPLITS HAPPEN WHEN FACIAL STRUCTURES THAT ARE GROWING BEFORE BIRTH DON'T FULLY CLOSE. CLEFT LIP AND PALATE ARE TWO OF THE MOST COMMON BIRTH DEFECTS. ABOUT ONE OR TWO CASES OCCUR IN EVERY 1,000 BIRTHS IN THE U.S.

CLEFT LIP IS WHEN A PERSON IS BORN WITH A SPLIT IN THE TOP OF HIS OR HER LIP.



CLEFT PALATE IS WHEN A PERSON IS BORN WITH A SPLIT IN HIS OR HER PALATE.

HOW A CLEFT LIP OR PALATE FORMS

THE TISSUES AND BONES OF A BABY'S UPPER JAW, NOSE AND MOUTH JOIN TOGETHER (FUSE) TO FORM THE ROOF OF THE MOUTH AND UPPER LIP. THIS HAPPENS DURING THE FIRST SIX TO 10 WEEKS OF PREGNANCY. A CLEFT HAPPENS WHEN PARTS OF THE LIP AND MOUTH DON'T FULLY JOIN TOGETHER.

A CLEFT LIP MAY LOOK LIKE A SMALL OPENING ON THE TOP LIP. IT COULD ALSO EXTEND INTO THE NOSE OR THE GUMS AROUND THE MOUTH. A CLEFT PALATE MIGHT ONLY AFFECT THE SOFT PALATE AT THE BACK OF THE MOUTH. IT COULD ALSO FORM A HOLE IN THE HARD PALATE NEAR THE FRONT OF THE MOUTH.

THE GOOD NEWS

BOTH CLEFT LIP AND PALATE CAN BE TREATED. FOR MOST CHILDREN, A SERIES OF SURGERIES STARTING IN THE FIRST YEAR OF LIFE CAN GIVE BACK THE NORMAL FUNCTIONS OF THE MOUTH, NOSE AND EARS. SURGEONS, DOCTORS AND SPECIALISTS CAN CREATE A NORMAL LOOK WITH VERY LITTLE SCARRING.

By Definition

UNILATERAL CLEFT: A CLEFT ON ONE SIDE OF THE MOUTH.

BILATERAL CLEFT: A CLEFT ON BOTH SIDES OF THE MOUTH.

MOST CLEFTS FIT INTO ONE OF THREE TYPES:

1. CLEFT LIP BY ITSELF – MOST COMMON IN BOYS
2. CLEFT PALATE BY ITSELF – MOST COMMON IN GIRLS
3. CLEFT LIP AND CLEFT PALATE TOGETHER – MORE COMMON IN BOYS

THE CAUSES OF CLEFT LIP/PALATE

HEALTH EXPERTS DON'T ALWAYS KNOW WHAT CAUSES A CHILD TO BE BORN WITH CLEFT LIP OR PALATE. MANY CLEFTS ARE THOUGHT TO BE CAUSED BY A COMBINATION OF:

- GENETICS, INHERITING THE GENES FOR THE CONDITION FROM THE MOTHER AND/OR FATHER
- CERTAIN MEDICATIONS, SUCH AS SOME ANTI-SEIZURE MEDS
- NOT GETTING THE RIGHT VITAMINS AND NUTRIENTS DURING PREGNANCY, SUCH AS FOLIC ACID
- THE MOTHER BEING EXPOSED TO CERTAIN CHEMICALS



CLEFTS HAPPEN MORE OFTEN IN CHILDREN OF ASIAN, LATINO OR NATIVE AMERICAN DESCENT.

FACING THE RISKS

BABIES WHOSE MOMS SMOKE, DRINK ALCOHOL AND USE DRUGS WHILE PREGNANT MAY ALSO RUN A HIGHER RISK FOR BIRTH DEFECTS. STUDIES SHOW THAT MOTHERS WHO BINGE DRINK DURING THE FIRST WEEKS OF PREGNANCY HAVE A GREATER RISK OF HAVING A BABY WITH A FACIAL BIRTH DEFECT LIKE CLEFT LIP OR PALATE.

HEALTH PROBLEMS LINKED TO CLEFT LIP/PALATE

→ FEEDING PROBLEMS

MOST BABIES BORN WITH A CLEFT LIP DON'T HAVE FEEDING PROBLEMS. BUT THOSE WITH CLEFT PALATE DO. SINCE THE PALATE PREVENTS FOOD AND LIQUIDS FROM GOING INTO THE NOSE, THESE BABIES SWALLOW A LOT OF AIR AND BRING UP FOOD INTO THE NASAL CAVITY. THEY ALSO HAVE A HARDER TIME BREAST-FEEDING.

DO THIS

IF YOUR BABY HAS FEEDING ISSUES, MAKE SURE HE OR SHE SEES A DOCTOR REGULARLY TO CHECK HIS/HER WEIGHT GAIN.

→ DENTAL PROBLEMS

SMALL, MISSING, EXTRA OR OUT OF PLACE TEETH ARE COMMON IN CHILDREN WITH CLEFT LIP AND PALATE. THEY MAY HAVE A DEFECT IN THE GUMS OR THE BONE THAT SUPPORTS THE TEETH. THESE DEFECTS CAN CAUSE TEETH TO MOVE, LEAN, DISPLACE PERMANENT TEETH OR KEEP THEM FROM COMING IN PROPERLY.

DO THIS

TAKE YOUR CHILD TO A PEDIATRIC DENTIST TRAINED IN CLEFT LIP AND PALATE. THE DENTIST WILL CHECK MOUTH GROWTH, LOOK FOR PROBLEMS AND TREAT THEM.

→ SPEECH PROBLEMS

ABOUT ONE IN FIVE CHILDREN WITH CLEFT PALATE HAS SPEECH PROBLEMS AFTER SURGERY. THE VOICE CAN SOUND NASALLY BECAUSE THE PALATE DOESN'T MOVE WELL ENOUGH TO KEEP AIR FROM LEAKING OUT OF THE NOSE. CLEFT LIP AND DENTAL ISSUES CAN LEAD TO OTHER SPEECH PROBLEMS AS A CHILD GROWS.

DO THIS

SEE A SPEECH THERAPIST TO CHECK YOUR CHILD'S SPEECH AND LANGUAGE SKILLS.

→ MIDDLE EAR FLUID AND HEARING LOSS

FLUID BUILDUP IN THE EARS OF BABIES WITH CLEFT PALATE CAN LEAD TO EAR INFECTIONS AND EVEN THE LOSS OF HEARING. TUBES PLACED IN THE EARDRUMS CAN DRAIN THE FLUID AND MAKE HEARING BETTER.

DO THIS

HAVE YOUR CHILD'S EARS AND HEARING CHECKED BY THE DOCTOR OR AUDIOLOGIST ONCE OR TWICE A YEAR.

TEAM SMILE

KNOW THE SPECIAL HEALTH CARE PROS WHO WILL WORK WITH YOU AND YOUR CHILD TO MAKE HIS OR HER SMILE THE BEST IT CAN BE!

PEDIATRICIAN

A DOCTOR FOR CHILDREN

THIS DOCTOR FOR YOUR CHILD'S OVERALL HEALTH WILL LINK YOU TO A TEAM OF SPECIALISTS.



GENETICIST

A SCIENTIST WHO STUDIES GENES

THIS SPECIAL BIOLOGY EXPERT WILL TRY TO DETERMINE WHAT EFFECT GENES AND HEREDITY MAY HAVE HAD IN FORMING CLEFT LIP AND PALATE.



PLASTIC SURGEON

A DOCTOR WHO HELPS FIX FACIAL CHALLENGES

FIXING ANY FACIAL DEFORMITIES FOR YOUR CHILD WILL BE THIS SKILLED SURGEON'S JOB.



AUDIOLOGIST

A SPECIALIST WHO HELPS HEARING
HE OR SHE WILL STUDY YOUR CHILD'S EARS AND THE TUBES THAT JOIN WITH THE THROAT TO MAKE HEARING BETTER.



DENTIST

A DOCTOR WHO KEEPS SMILES HEALTHY
CHILDREN BORN WITH CLEFT LIP AND PALATE MAY HAVE MANY DENTAL ISSUES. A SPECIAL DENTIST WHO DEALS WITH CLEFTS WILL HELP GIVE YOUR CHILD A WINNING SMILE.



NURSE

A PERSON WHO HELPS THE DOCTOR CARE FOR PEOPLE'S HEALTH

A SPECIAL NURSE MAY BE ASSIGNED TO YOUR CHILD, GIVING REGULAR CARE AND SHARING INFORMATION WITH THE DOCTORS. LET HIM OR HER KNOW OF ANY CONCERNS YOU MIGHT HAVE.



SPEECH THERAPIST

A PERSON WHO HELPS SPEAKING
AS YOUR CHILD GROWS, HIS OR HER SPEAKING ABILITY WILL BE GREATLY HELPED BY A SPEECH THERAPIST.



ORTHODONTIST

A DOCTOR WHO STRAIGHTENS TEETH

IF YOUR CHILD NEEDS BRACES TO HELP TEETH GROW IN STRAIGHT, THIS DOCTOR CAN FIT HIM OR HER. A BEAUTIFUL STRAIGHT SMILE WILL RESULT IN TIME!



OTHER HELPFUL TEAM MEMBERS IN YOUR CHILD'S JOURNEY MAY BE:

- AN ORAL SURGEON
- A SOCIAL WORKER
- AN EAR, NOSE AND THROAT DOCTOR
- A PSYCHOLOGIST OR THERAPIST
- A TEAM COORDINATOR

SURGERY

CLEFT LIP: WHEN A CHILD IS 3 MONTHS OLD, SURGERY CAN MEND A CLEFT LIP. IF THE CLEFT IS WIDE, THE DOCTOR MAY USE A LIP ADHESION OR MOLDING PLATE TO HELP BRING THE PARTS OF THE LIP CLOSER TOGETHER BEFORE THE LIP IS FULLY REPAIRED. CLEFT LIP SURGERY OFTEN LEAVES A SMALL SCAR UNDER THE CHILD'S NOSE.

CLEFT PALATE: SURGEONS CAN MOST OFTEN FIX A CLEFT PALATE. STARTING WHEN A BABY IS 9 TO 12 MONTHS OLD, SURGEONS JOIN THE MUSCLES OF THE SOFT PALATE AND MOVE THE TISSUES TO CLOSE THE CLEFT. THE AIM OF THIS KIND OF SURGERY IS TO HAVE CHILDREN SPEAKING CLEARLY AS THEY GROW.

LIKE FELICITY IN OUR STORY, A CHILD MAY NEED MORE SURGERIES AS HE OR SHE GROWS. FACIAL STRUCTURE CHANGES WITH AGE. SURGERIES TO HELP MAKE SPEECH BETTER, CLOSE GAPS AND MAKE THE MOUTH MORE STABLE FOR TEETH MAY BE NEEDED. A BONE GRAFT CAN CLOSE THE GAP IN THE BONES OR GUMS NEAR THE FRONT TEETH. THIS IS DONE WHEN CHILDREN ARE BETWEEN 6 AND 10 YEARS OLD.

WHEN CHILDREN BECOME TEENS, THEY MAY WANT TO HAVE SCARS MADE LESS NOTICEABLE. SURGERIES CAN HELP THE LOOK OF THEIR NOSE AND UPPER LIP. ORAL SURGERY AT THIS TIME CAN FIX OVERBITE, SPEECH AND BREATHING PROBLEMS AND APPEARANCE.

CRANIOFACIAL ABNORMALITIES

IN OUR STORY, FELICITY MEETS A FRIEND NAMED BALDWIN. UNLIKE HER CLEFT LIP AND PALATE, BALDWIN WAS BORN WITH A **CRANIOFACIAL DEFORMITY**. THERE ARE DIFFERENT TYPES OF CRANIOFACIAL DEFORMITIES, SUCH AS **CRANIOSYNOSTOSIS**, IN WHICH THE BONES IN THE FACE GROW DIFFERENTLY. THE JOINTS BETWEEN THE BONES IN THE FACE CLOSE TOO EARLY, BEFORE THE BRAIN IS FULLY FORMED.



CRANIOFACIAL DIFFERENCES MAY BE CAUSED BY ABNORMAL GROWTH PATTERNS OF THE FACE OR SKULL, INVOLVING THE SOFT TISSUE AND BONES. THE DISFIGURING CONDITION MAY BE BROUGHT ABOUT BY BIRTH DEFECTS, DISEASE OR TRAUMA.

LIKE CLEFT LIP AND PALATE, CRANIOFACIAL DEFORMITIES MAY BE CAUSED BY GENES FROM THE PARENTS, ENVIRONMENTAL EFFECTS AND THE MOTHER NOT GETTING ENOUGH FOLIC ACID DURING PREGNANCY.

TREATING CRANIOFACIAL ABNORMALITIES

MANY OF THE SAME HEALTH TEAM EXPERTS FOR CLEFT LIP AND PALATE WORK WONDERS WITH CRANIOFACIAL DEFORMITIES. LIKE CLEFT LIP AND PALATE, PLASTIC SURGERY FOR CHILDREN WITH CRANIOFACIAL ISSUES HAS BEEN VERY SUCCESSFUL.

EVERY DAY, RESEARCHERS LOOK FOR NEW WAYS TO HELP THESE CHILDREN AND FIX THE ISSUES, SUCH AS:

- CRAFTING NEW BONES: FINDING NEW WAYS TO SPUR ON GROWTH IN THE CHILD'S OWN BONES SO BONE GRAFTS WON'T BE NEEDED
- MAKING SURGERY TECHNIQUES AND TOTAL PATIENT CARE BETTER
- MONITORING PROGRESS TO SEE HOW TREATMENT AFFECTS CHILDREN'S QUALITY OF LIFE



IF YOUR CHILD WAS BORN WITH CRANIOFACIAL DEFORMITIES, TALK TO YOUR DOCTORS AND FOLLOW THEIR PLAN. SEE THE RESOURCES AT THE END OF THIS BOOKLET FOR INFO AND SUPPORT IDEAS.

EMOTIONAL AND SOCIAL ISSUES

CHILDREN WITH FACIAL DIFFERENCES JUST WANT TO BE TREATED THE SAME AS OTHERS. MISSING SCHOOL FOR APPOINTMENTS, TROUBLE SPEAKING AND HAVING EDUCATIONAL CHALLENGES CAN BE HARD FOR THESE CHILDREN.



WHY DOES YOUR SMILE
LOOK LIKE THAT?

TEASING, BULLYING AND BEING ASKED A LOT OF QUESTIONS CAN MAKE YOUR CHILD FEEL ANGRY, SAD, EMBARRASSED, HURT AND LONELY. LISTEN TO YOUR CHILD AND TALK ABOUT THESE FEELINGS. TEACH YOUR CHILD WAYS OF DEALING WITH THESE EVENTS. FINDING THE RIGHT WORDS TO SAY, TALKING WITH A FRIEND OR DRAWING A PICTURE ARE GOOD OUTLETS FOR A CHILD WHOSE FEELINGS HAVE BEEN HURT.

PSYCHOLOGISTS AND SOCIAL WORKERS ON YOUR CHILD'S TEAM CAN HELP GUIDE YOU THROUGH THESE DIFFICULT TIMES. TURN TO THEM IF YOUR CHILD NEEDS ADDED SUPPORT.

MOST CHILDREN WITH CLEFT LIP, CLEFT PALATE OR CRANIOFACIAL DEFORMITIES GROW UP TO BE HEALTHY, HAPPY ADULTS.

TIPS FOR TEENS

THE TEEN YEARS ARE TOUGH TIMES FOR ANYONE. KEEP THE LINES OF COMMUNICATION OPEN BETWEEN YOU AND YOUR CHILD DURING THIS TIME. HERE ARE SOME TIPS TO HELP YOU DO THAT:

→ URGE HIM OR HER TO BE CONFIDENT. DON'T LET THE CLEFT OR FACIAL DIFFERENCES DEFINE WHO HE OR SHE IS AS A PERSON.

→ SUPPORT FRIENDSHIPS AND RELATIONSHIPS FOR YOUR CHILD. SET A GOOD EXAMPLE BY MAKING FRIENDS WITH PEOPLE WHO ARE DIFFERENT FROM YOU.

→ BEING INVOLVED IN SPORTS, MUSIC, ARTS, SCHOOL CLUBS AND OTHER ACTIVITIES IS A GREAT WAY TO TEACH YOUR CHILD SELF-WORTH.

→ GIVE YOUR CHILD THE POWER TO MAKE SOME OF HIS OR HER OWN CHOICES. FROM SMALL TO BIGGER CHOICES, YOUR CHILD WILL BE ABLE TO BECOME MORE INDEPENDENT LATER ON.

→ URGE YOUR CHILD TO TALK ABOUT HIS OR HER CONDITION WITH THE CLASS. YOU MAY ASK A MEMBER OF THE HEALTH TEAM TO SPEAK AS WELL. THE COURAGE TO SPEAK IN FRONT OF THE CLASS COULD GO A LONG WAY TO INSTILL CONFIDENCE.



RESOURCES

CLEFT PALATE ASSOCIATION

CLEFTLINE.ORG

24-HOUR HOTLINE: 800-24-CLEFT

CLEFT LIP/PALATE & CRANIOFACIAL SPECIALISTS IN YOUR AREA

CLEFTLINE.ORG/PARENTS-INDIVIDUALS/
TEAM-CARE/

CLEFT ADVOCATE

CLEFTADVOCATE.ORG

FACES: THE NATIONAL CRANIOFACIAL ASSOCIATION

FACES-CRANIO.ORG

CHILDREN'S CRANIOFACIAL ASSOCIATION

CCAKIDS.COM

BIRTH DEFECT RESEARCH FOR CHILDREN, INC.

BIRTHDEFECTS.ORG

FRIENDLY FACES

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EVERY FACE IS SPECIAL.

**AND EACH ONE DESERVES
ITS OWN SPECIAL SMILE.**

FOR CHILDREN BORN WITH CLEFT LIP,
CLEFT PALATE OR CRANIOFACIAL
DEFORMITIES, IT CAN TAKE A TEAM
OF SMILE EXPERTS TO BRING OUT
THE BEST SMILE.

USE THIS BOOKLET TO LEARN ABOUT
THE CAUSES AND TREATMENT FOR
THESE CONDITIONS, AS WELL AS THE
SPECIAL HEALTH TEAM MEMBERS WHO
WORK TO HELP YOUR CHILD.

CHILDREN BORN
WITH CLEFT LIP, CLEFT
PALATE AND CRANIOFACIAL
DEFORMITIES HAVE A JOURNEY
THAT'S DIFFERENT FROM MOST.
BUT A TEAM OF DOCTORS AND
SPECIALISTS CAN HELP THESE
CHILDREN LOOK THEIR BEST,
SPEAK AND HEAR CLEARLY
AND IMPROVE THEIR
QUALITY OF LIFE.



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KEEP THE PLANET
HEALTHY! THIS BOOK
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