

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR**

ACTION REFERRAL

TO <i>Bowling</i>	DATE <i>10/16/06</i>
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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>000308</i>	<input checked="" type="checkbox"/> Prepare reply for the Director's signature DATE DUE <i>10/23/06</i>
2. DATE SIGNED BY DIRECTOR <i>[Signature]</i>	<input type="checkbox"/> Prepare reply for appropriate signature DATE DUE _____
	<input type="checkbox"/> FOIA DATE DUE _____
	<input type="checkbox"/> Necessary Action

APPROVALS <small>(Only when prepared for director's signature)</small>	APPROVE	* DISAPPROVE <small>(Note reason for disapproval and return to preparer.)</small>	COMMENT
1.			
2.			
3.			
4.			

JOE WILSON
2ND DISTRICT, SOUTH CAROLINA

ASSISTANT MAJORITY WHIP

COMMITTEES:
ARMED SERVICES

INTERNATIONAL RELATIONS
EDUCATION AND THE WORKFORCE
HOUSE POLICY

Congress of the United States
House of Representatives

COUNTIES:

AIKEN*
ALLENDALE
BARNWELL
BEAUFORT
CALHOUN*
HAMPTON
JASPER
LEXINGTON
ORANGEBURG*
RICHLAND*
(*PARTS OF)

ERIC DELL
CHIEF OF STAFF

October 13, 2006

RECEIVED
OCT 13 2006

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Mr. Robert M. Kerr
Director
SC Department of Health and Human Services
Post Office Box 8206
Columbia, South Carolina 29202-8206

RE: Ms. Jackie Chavis for her son
Bobby Lee Brewer

Dear Mr. Kerr,

I am writing to you on behalf of the above named constituent who has contacted me regarding her son and his need for teeth implants. Enclosed is a copy of all correspondence for your perusal. Any assistance that you could offer would be most appreciated.

It is an honor to represent the people of the Second Congressional District, and I value your input.

Please respond to the Midlands District Office at 1700 Sunset Blvd., West Columbia, South Carolina 29169; Fax number 803-939-0078. Thank you for your time and concern in this and all other matters.

Yours very truly,



JOE WILSON
Member of Congress

JW/jmc
Enclosure

MIDLANDS OFFICE:
1700 SUNSET BLVD. (US 378), SUITE 1
WEST COLUMBIA, SC 29169
MAILING ADDRESS: P. O. BOX 7381
COLUMBIA, SC 29202
(803) 939-0041
FAX: (803) 939-0078

212 CANNON HOUSE OFFICE BUILDING
WASHINGTON, DC 20515-4002
(202) 225-2452
FAX: (202) 225-2456
E-MAIL: joe.wilson@mail.house.gov
WEBSITE: www.house.gov/joewilson

LOWCOUNTRY OFFICE:
903 PORT REPUBLIC STREET
P. O. BOX 1538
BEAUFORT, SC 29901
(843) 621-2530
FAX: (843) 621-2535

9/30/06

Dear Adam -

There is some information on ECC, the genetic condition may be you can use hearing aids, that causes him to need tooth implants,

I spoke to you on the phone about 2 weeks ago and told you my son has been told for years that would be getting those dental implants by age 12 doctor at the Craniofacial clinic at a Richard Medical Park. Since he only has seven permanent teeth & is near at the age when this procedure is supposed to take place, I've been informed that those don't even any establishment or insurance that pays for those. He has medical that either them or CR's (children's Rehab Services) pay for them. I've asked The CR's, Craniofacial clinic and his oral surgeon (Dr. Johnson) how people pay for these implants & they said they never had one of the kids from the Craniofacial clinic actually come into to get them, they said no one covers them that they know of.

I called the Medicaid state office & they said implants, like hearing aids, are non-covered items even if they are medically necessary. I've paid \$800.00 for each of my sons' hearing aids. However, I am on disability & I can't afford \$800.00 for each tooth & that is the price I've been quoted. ✓

I've become separate for help in this matter, my son desires that any medical notations + he wants what his told, those implants would do for him. He wants to be able to see just + to have opening teeth that will allow him to speak up good. Of course he would also simply have a smile that he's always been proud + wants for a long, long time.

I've included pictures of my son, ~~implants~~ on his genetic condition and on dental implants. Please find out if there is anything you know on you can come up with to help us.

Thankyou,

Dequeline K. Charra
(Robert'sa Brava's mom),

Jackie Charra
161 Mack St.

Gastonia, S.C. 29053
(803) 939-4802.



← This is one of our most recent pictures of Babyree Gabriel.

STATE OF SOUTH CAROLINA
HEALTH AND ENVIRONMENTAL CONTROL
CERTIFICATE OF LIVE BIRTH

139 90 030136
BIRTH NUMBER

1. CHILD'S NAME First **ROBERT** Last **BREWER** 2. DATE OF BIRTH (Month, Day, Year) **July 29, 1990** 3. TIME OF BIRTH **11:22a**

4. SEX **male** 5. CITY, TOWN, OR LOCATION OF BIRTH **West Columbia** 6. COUNTY OF BIRTH **Lexington**

7. PLACE OF BIRTH: Hospital Clinic/Doctor's Office Freestanding Birthing Center 8. FACILITY NAME (If not institution, give street and number) **Lexington Medical Center**

9. I certify that this child was born alive at the place and time and on the date stated. 10. DATE SIGNED (Month, Day, Year) **7-29-90** 11. ATTENDANT'S NAME AND TITLE (If other than certified (Type/Print) Name **John Neyle Bennett** M.D. M.D. C.N.M. Other (Specify) _____

12. CERTIFIER'S NAME AND TITLE (Type/Print) Name **Ijan W. House** 13. ATTENDANT'S MAILING ADDRESS (Street and Number or Rural Route Number, City or Town, State, Zip Code) **132 E. Hosp. Dr. W. Cola, SC, 29169**

14. REGISTRAR'S SIGNATURE *Jacqueline Kay* 15. DATE FILED BY REGISTRAR (Month, Day, Year) **Aug. 01, 1990**

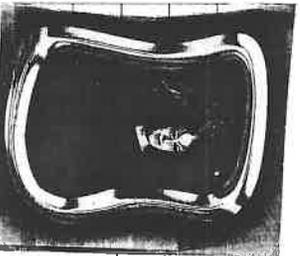
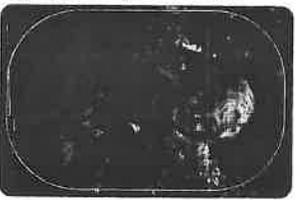
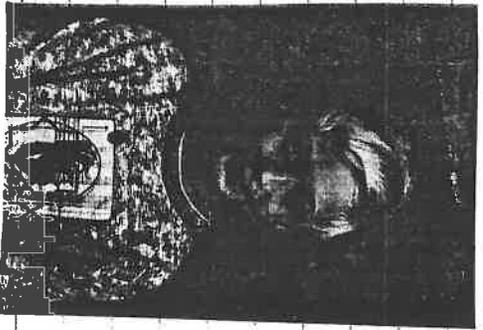
16a. MOTHER'S NAME First Middle Last **Jacqueline Kay Giles** 16b. MAIDEN SURNAME **Giles** 17. DATE OF BIRTH (Month, Day, Year) **4-21-68**

18. BIRTHPLACE (State or Foreign Country) **Virginia** 19a. RESIDENCE - STATE **SC** 19b. COUNTY **Lex** 19c. CITY, TOWN OR LOCATION _____

19d. STREET AND NUMBER **330 J Windmill Ct.** 19e. ZIP CODE **29210** 19f. INSI Yes No

21. FATHER'S NAME First Middle Last 22. DATA

24. I certify that the personal information provided on this certificate is correct to the best of my knowledge. Signature of Parent or Other Informant *Jacqueline Kay Giles*





Greenwood Genetic Center

Columbia Office
529 Richland Street
Columbia, SC 29201
(803) 799-5390 • FAX (803) 799-5391

PATIENT: Robert "Bobby Lee" Brewer

DATE OF BIRTH: 7-29-90

CHART NUMBER: 2694

LOCATION: Craniofacial Clinic

DATE OF EXAM: 9-28-01

CHIEF COMPLAINT: Ectrodactyly-ectodermal dysplasia-clefting syndrome

HISTORY OF PRESENT ILLNESS: Bobby Lee is now an 11 year old boy who was last seen in 1994 and given the diagnosis of Ectrodactyly-ectodermal dysplasia-clefting syndrome. Since that time he has done well with no major problems. He has had some procedures since then including PE tubes, a palatoplasty in 1997, and a fistula repair and bone graft of his palate in 1997.

His vision is followed by Dr. McWilliams, who has diagnosed nearsightedness. He is awaiting glasses at this time. His hearing shows severe loss bilaterally which is conductive in nature. He had a bilateral mastoidectomy in the past as well. He does not take any medications.

DEVELOPMENT: Bobby Lee is currently in the 5th grade in regular classes except for language arts and math for which he requires resource. He is in speech therapy secondary to pronunciation.

SOCIAL HISTORY: Bobby Lee lives in Gaston, SC with his mother, stepfather, and brother. They have a cat and dog at home. He enjoys jumping on the trampoline, jumping rope, riding bikes, and plenty of video games.

FAMILY HISTORY: This was reviewed and of note, there are no other members of the family with ectodermal dysplasia, ectrodactyly, or clefting (or any variation of this combination).

Clinical Staff

Kate B. Clarkson, M.D.
Clinical Geneticist

Ken Corning, M.S.
Genetic Counselor

Amy Toburen, M.S.

PHYSICAL EXAM:

GENERAL: Bobby Lee is a very nice 11 year old boy in no apparent distress
HEAD CIRCUMFERENCE: 54 cm (50th percentile)
HEAD: normocephalic
EARS: normal architecture
EYES: PERRL; extraocular movements are intact
NOSE: hypoplastic left nasal ala
MOUTH: shows repair of his cleft palate; repair of the left clefting of his lip; he has a corrective appliance
NECK: supple
LUNGS: clear to auscultation bilaterally
HEART: regular rate and rhythm without murmur
ABDOMEN: benign
BACK: normal curve without evidence of scoliosis
UPPER LIMBS: his left hand has a thumb and a 4th and 5th finger with an intervening cleft. He has had operations on this hand to release syndactyly. His left hand shows fingers 1 and 2, 4 and 5 are present. There is a cleft between fingers 2 and 4. He has also had operations on this hand to release syndactyly.
LOWER LIMBS: full range of motion with normal flexion creases; there is no evidence of clefting or syndactyly
SKIN: very light complexion; blonde hair and sparse eyelashes; he has hypoplastic light colored nipples
NEUROLOGICAL: nonfocal

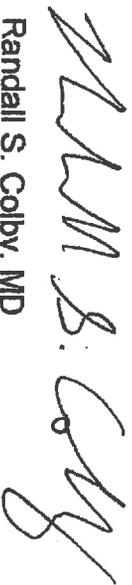
SUMMARY: Bobby Lee is a very nice 11 year old boy who has Ectrodactyly-ectodermal dysplasia-clefting syndrome. In recent years it has been discovered that this syndrome is caused by changes in a gene called p63. We have obtained Bobby Lee's blood today and will test him for this at the Greenwood Genetic Center. This is currently a research test and the results may take some time. Once we get the results back, we will contact his family immediately.

Because of the renal problems associated with this syndrome, we recommend that Bobby Lee have a screening renal ultrasound some time in the next year or two to rule out any structural malformations of his kidneys or urinary system.

This condition is an autosomal dominant condition which appears to have begun with Bobby Lee. This means that when he is older and has children of his own, he will have a 50% or 1 in 2 chance of passing this condition on to each of his children.

Robert "Bobby Lee" Brewer
September 28, 2001
page 3

We enjoyed seeing Bobby Lee and his mother and look forward to seeing them again in 1 year for a follow-up examination. If there are any questions or concerns in the meantime, they may give us a call.



Randall S. Colby, MD
Clinical Geneticist

RSC/df

cc: Philip Mubarak, MD
1301 Taylor Street, Suite 5-K
Columbia, SC 29201

Jacqueline Chavis
161 Mack Street
Gaston, SC 29053

Craniofacial Clinic
2 Richland Medical Park
Columbia, SC 29203

Wilson G. McWilliams, MD
P.O. Box 1754
Columbia, SC 29202