



Audiology Barriers to Cochlear Implantation for Children with Hearing Loss

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Oberkotter Foundation &
Hearing First

Road Map

- **Primary Objective:** Discuss the audiology barriers to cochlear implant access for children and describe a new multi-disciplinary initiative to improve access to those who may benefit
- Brief overview of cochlear implant access for children
- Brief description of the **CI-PATH Pediatric Initiative**
 - Cochlear Implant Patient Access to Hearing – Pediatric Initiative
- Summary of barrier to cochlear implants for children
- Potential solutions to improve cochlear implant access for children



The Problem

- Almost all children in the US receive newborn hearing screening. According to the CDC, in the US, approximately 1/1000 children are born with profound hearing loss (HL) annually and up to 2-3/1000 with moderate to severe or greater hearing loss. Cochlear implantation is a safe and reliable treatment for children with severe to profound hearing loss. **The primary benefit of cochlear implants is the delivery of auditory information to the child's brain, which, with appropriate family-focused therapy, promotes overall cognitive development including spoken language and literacy.**¹
- **Despite the established evidence on the benefit of cochlear implants in children, only 50% of eligible children in the US receive one** ². This compares with pediatric cochlear implant access rates of 90% or more in several European countries, Australia, and NZ according to WHO³.

The Goal – CI-PATH

Every parent of a child with severe to profound hearing loss in the US will have timely referral and accurate information about CI required to make an informed decision about their child's hearing.

- *By 2032, the adoption % for CI will increase to 70% for children.*



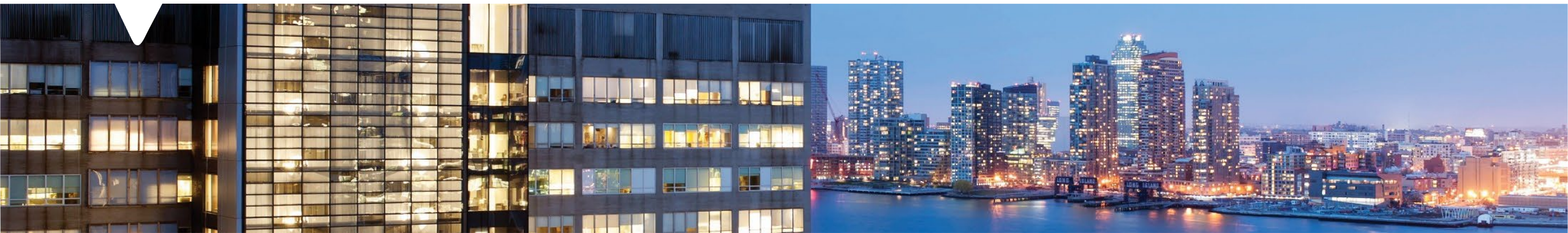
Additional Challenges

- Research indicates the pediatric cochlear implant access rate may be lower for certain groups of children
 - SES, parental educational levels, rural, race/ethnicity

Department of Otolaryngology

CEILING EFFECTS IN PEDIATRIC SPEECH PERCEPTION TESTING

Emily Spitzer AuD, Alexandra Lichtl BA, David Landsberger PhD, & Susan Waltzman PhD





Study Inclusion Criteria

Ceiling effects for speech perception tests in pediatric cochlear implant users

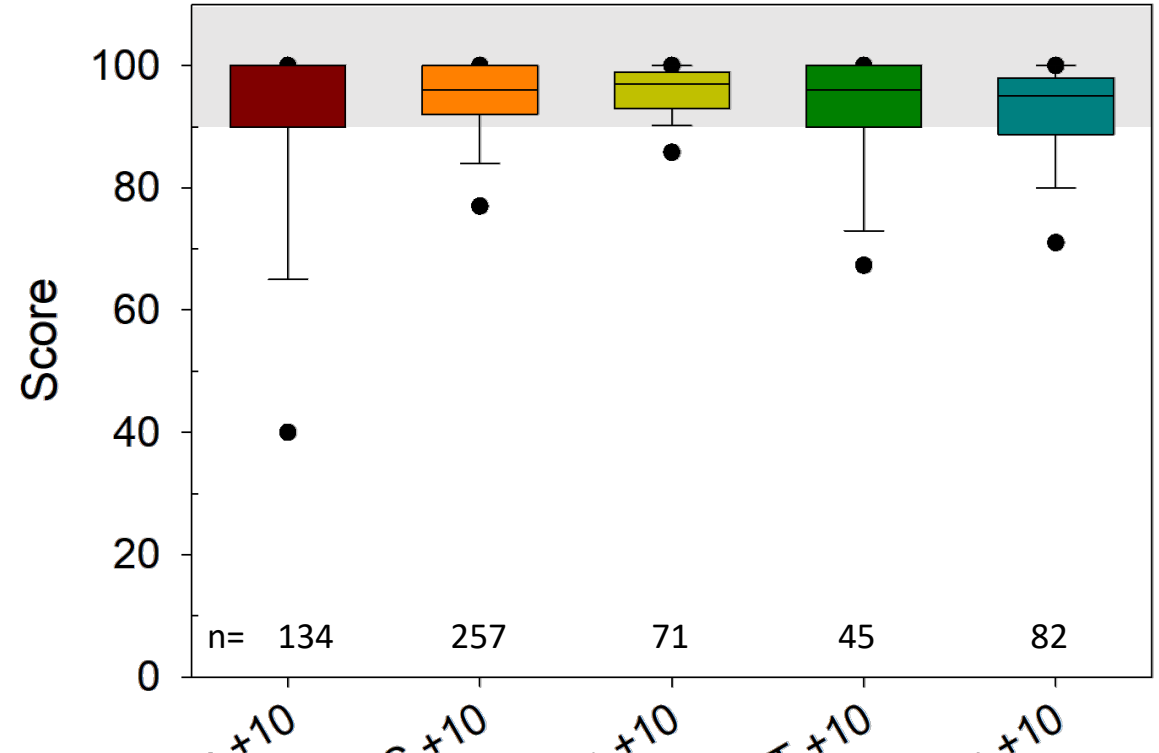
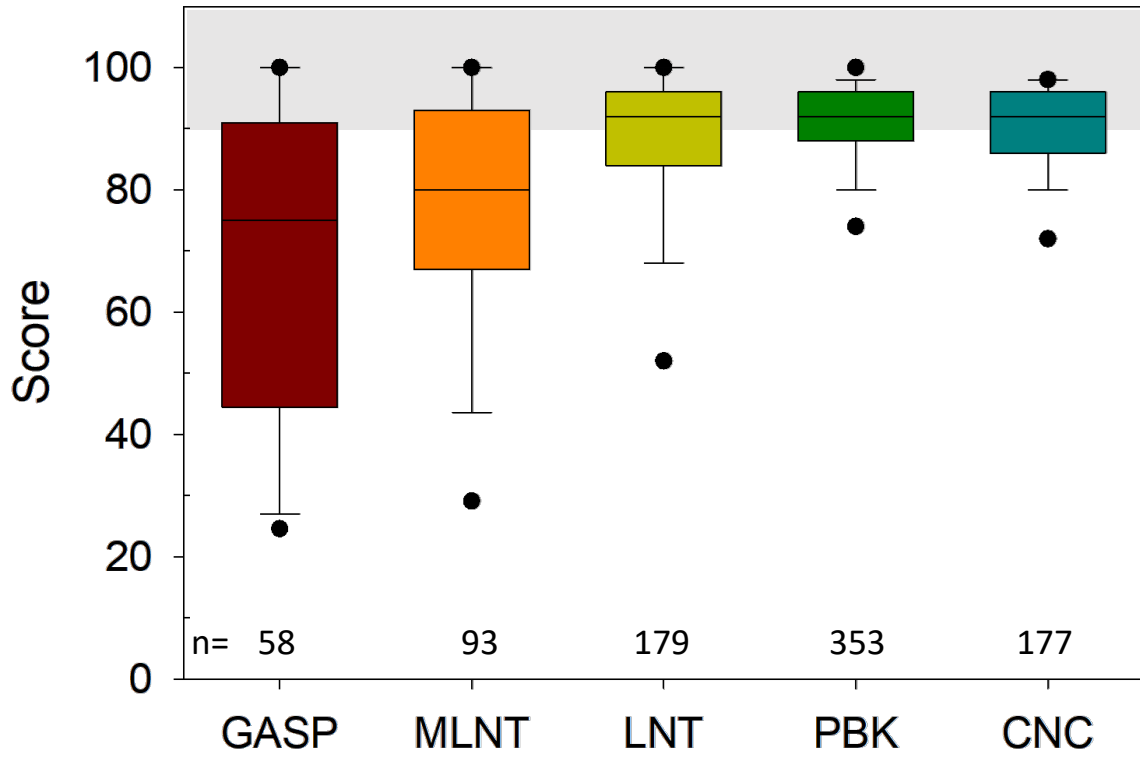
Emily R. Spitzer, David M. Landsberger, Alexandra J. Lichtl & Susan B. Waltzman

n=165

- Implanted between 2005 and 2014
- Mean age at implantation: 1.51 years (SD: 0.92), range: 0.5-3.98 years
- Age range at test: 0.92-18.52 years
- CI experience range at test: 0.28-17.37 years
- Exclusions: malformations, incomplete insertions, English as the non-dominant language, nonuse
- Over 900 total data points

Ceiling: $\geq 90\%$ correct

Average Test Scores



Percentage Hitting Ceiling



*Every Problem Is An
Opportunity In Disguise.*

- JOHN ADAMS -

The Cochlear Implant Patient Access to Hearing Pediatric Initiative



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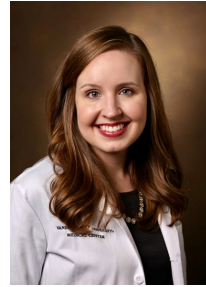
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Barriers to Cochlear Implant Access for Children

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Review Article

Parent reported barriers and facilitators towards cochlear implantation – A systematic review

Rohit Ravi, Dhanshree R. Gunjawate*

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Parent Reported Barriers – Ravi & Gunjawate, 2020

- Systematic review of electronic databases to identify publications examining barriers and facilitators to cochlear implantation for children
- Included 19 studies in review
- Summarized barriers and facilitators
 - Barriers – 6 Categories
 - Facilitators – 4 Categories

The Barriers to CI Access

Professional confidence
EHDI process gaps/staffing changes
Distance
Misinformation/bad experience
Lack of coordinated care/silos
Lack of exposure to CI
Limited # of peds CI centers

Timely Referral



Language barriers
Lack of prof training
Candidacy criteria not understood or believed
Stigma/"failure" based
Treatment Misinformation
Lack of alignment on performance & expectations
Messaging unclear/negative

Lack of Awareness



Too much time required for appts.
Time commitment constraints
Lack of follow-up
Transition time between professionals
Poor evidence to support impact beyond hearing – "whole child"

Process



Fear of surgery risks – risk is not understood
Future access to genetic, pharma, future therapies
Brain surgery
Misinformation on reliability
Cosmetics

Fear of Surgery



Poor Medicaid reimbursement
High deductibles/Co-Pays/OOP expenses
Professional attrition to higher paying jobs
Providers not referring b/c of reimbursement levels
High # of denials/appeals

Lack of Funding



Spiritual beliefs
ASL/Cultural beliefs/Political agendas
Fear of COVID exposure
Other health issues
No direct exposure in family or community to someone with a CI
Lack of professional advocacy
Inequitable access (based on race, geography)



Social Barriers



UNC Study – Park, et al., 2021

The Laryngoscope
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Sound Opportunities: Factors That Impact Referral for Pediatric Cochlear Implant Evaluation

Lisa R. Park, AuD ; Elizabeth Preston, AuD; Hannah Eskridge, MSP; English R. King, AuD;
Kevin D. Brown, MD, PhD 

- Objective: Identify barriers to and opportunities for referral among children who could be considered for cochlear implantation
- Reviewed clinical database at UNC-affiliated audiology clinics to identify children seen over the past 5 years who meet UNC's evidence-based guidelines for referral for pediatric cochlear implant candidacy assessment
 - Pure tone average of 65 dB HL or poorer
 - Speech Intelligibility Index of .65 or poorer
 - Aided word recognition of 60% or poorer

} Ear specific

Hearing Loss Categories

TABLE I.
Hearing Loss Categories Used to Describe Groups.

Hearing Loss Category	Definition
Traditional	Both ears ≥ 80 dB PTA
SSD	Poorer ear ≥ 80 dB PTA Better ear ≤ 15 dB HL
Bilateral nontraditional	Both ears < 80 dB PTA and met referral criteria
Asymmetric	Poorer ear ≥ 80 dB PTA Better ear > 15 dB HL but did not meet referral criteria
Traditional + Nontraditional	One ear ≥ 80 dB PTA Contra ear < 80 dB PTA and met referral criteria

PTA = pure tone average at 500, 1000, and 2000 Hz; SSD = single-sided deafness.

Results

- 869 children met UNC's evidence-based guidelines
- 48% were referred for CI candidacy assessment
- 92% of "traditional" bilateral candidates were referred
- 82% were referred when they met "traditional" criteria in one ear and "non-traditional" in the other
- Poorest referral rates were for SSD candidates (26%), bilateral "non-traditional" candidates (27%), and asymmetric candidates (34%)

Reasons for No CI Referral

Out of 198 children who were not referred, 113 reported reasons for not pursuing CI assessment

Reason	% Occurrence	N
Provider stated they were not a candidate at the time	25.7%	29
Family stated they were not interested	19.5%	22
Choosing to wait for an unspecified event	9.7%	11
Leaving the decision to the child	8.0%	9
Family feels they are doing well	7.0%	8
Choosing to wait for a progression in hearing loss	6.2%	7
Cosmetic concerns	4.4%	5
Fear of losing residual hearing	4.4%	5
Fear of surgery	4.4%	5
Financial concerns	4.4%	5
Family felt that benefits would not outweigh risks	3.5%	4
Culturally deaf family	2.7%	3

Park et al., Discussion

in either ear. Of the 420 children who were referred, 90% (n = 378) were seen for an evaluation and a CI was recommended for 97% of those subjects (n = 367). If borderline candidates were being referred, we would expect that a more significant number of those referred would not qualify for an implant as they were making progress with hearing aids. Typically, children offered a CI as a treat-

Park et al., Discussion

did not mention why a referral was not pursued. For the 113 records that did note reasons for not pursuing referral, the reasons noted in Table IV indicate that families and providers were making decisions against implantation without a formal evaluation or counseling by CI providers. Families should be appropriately referred to and counseled by the pediatric CI team before candidacy decisions are made.

A3 Process – CI-PATH Pediatric Initiative



A3 Problem Solving	
Title:	Owner / Date:
1. Background / Problem Reduced access to CI	5. Proposed Counter Measures
2. Current Condition Only 50% of USA children who may benefit from a CI receive a CI	6. Plan
3. Goal / Target Condition By 2032, the adoption % for CI will increase to 70% for children	7. Follow-Up & Review
4. Root Cause Analysis	

Root Cause Analysis

Complex process

Siloed, uncoordinated care

- Unclear Pathway**
- Many specialists involved
 - Screening, diagnosis and treatment paths are specialized; often independent
 - Non hearing care professionals, like pediatricians, often not aware or involved
 - *Poor understanding/agreement of the local ecosystem and SoC treatment pathway for HL by severity and therapeutic outcome; no "best practices" for SoC*

- Variability in EHDI programs**
- Lack of consistency state by state in EHDI programs, high turn-over
 - Some see peds at high frequency, other low, lack of exposure and mentors
 - High loss to f/u 20%
 - Middle step of referring back to EHDI is not always tracked
 - *Lack of national registry and state policy to track hearing treatment and outcomes post screening to support/mandate appropriate referrals*

- Inefficient CI process**
- Too many & too long clinic appts
 - Lack of trust among referring professionals diagnostic testing-repeat batteries
 - *No standard test batteries; varies by specialty; professional variability*
 - *Unclear referral criteria and coordination between specialized professionals (HA to CI)*
 - Creates unnecessary appts and additional testing that increases cost of care (reimbursement challenges)
- Disconnect between HA and CI programs**
- Separation of HA & CI programs; No perceived incentive to merge/coordinate
 - Limited # of CI programs/ CI AuD's want to stay "elite"
 - Professional silos limit trusted referral relationships and access to CI
 - *Lack of accurate and timely professional training on CI limits knowledge and experience to support referral and integration process for expanding CI indications and innovations across care points*

Lack of Awareness

Misinformation about CI

- Hearing Loss not routinely considered as part of developmental health**
- Lack of knowledge on hearing health and language development
 - Not routinely part of training for professionals (or parents)
 - Lack common language on Hearing Health to include in education
 - Audiogram and relationship to speech and language development is complex
 - Difficult for referring professionals, pediatricians, to know appropriately counsel families on hearing loss and appropriate treatments
 - *Lack simple metric for hearing health and explanation for treatment continuum of care that includes CI for children with outcomes specific to development*

- Conflicting/Negative messaging on CI**
- CI Messaging is not clear or consistent across channels and voices (polarized)
 - "failure-based message"
 - "no guarantee" surgery
 - Negative public information about CI (history, media hype, desire to respect Deaf culture)
 - Bias and personal agendas influencing perception, counseling and treatment referrals (self, peer and PCP)
 - Not familiar with appropriate candidacy criteria, outcomes and expectations
 - Information can be in jargon and complex for those not in hearing channel
 - *Poor communication of the importance to development and evidence beyond hearing i.e QOL, education, productivity for targeted audiences (parent, referring professional segments, media)*

Lack of timely professional referral

Lack of professional knowledge leads to delays in referrals

- Low referral from pediatric ENT/HA/Ped Auds**
- *Lack of knowledge on candidacy and effectiveness*
 - *Not part of training programs*
 - No consistent test battery or guidelines for referral, no consequence of not referring
 - No relationship with CI center
 - Aud services poorly reimbursed compared to hearing aids, CI not perceived as profitable/viable for inclusion in program
 - CI centers separate and fewer than HA centers
 - Auds have limited or no experience with CI

- Primary Care Professionals/ Educators lack confidence in CI and making a referral**
- Lack of CI knowledge, lack of CI exposure
 - Uncertain of candidacy criteria / when to refer
 - Not part of training programs
 - Complex language, lacks simple metrics for primary care to base referrals for appropriate treatments
 - CI is messaged as a failure-based technology vs continuum of care
 - Fear of making a "bad" referral
 - Limited # of CI centers, no relationship with trusted CI professional to refer families- unclear treatment pathway
 - Lack of reciprocal communication on CI outcomes across care points

Every parent of a child with severe to profound hearing loss in the US will have timely referral and accurate information about CI required to make an informed decision about their child's hearing.

Reimbursement Challenges for Pediatric CI services

- Low Medicaid payment for CI services**
- Medicaid payment below Medicare and Commercial insurers; often does not cover professional time or facility costs
 - Varies by state administration
 - High volume of denials and appeals
 - Lack of economic evidence provided to support value
 - Many services given away setting precedent of low value
 - Financial disincentive to offer CI services
 - *Lack of professional advocacy to support reimbursement*

- Lack of audiology advocacy for services reimbursement**
- High AuD attrition
 - Lack of knowledge on audiology reimbursement
 - Lack of education on reimbursement
 - Multiple professional societies; clinicians often must select one to pay annual dues
 - Lack of time and PAC investment in advocacy
 - Low engagement in consistent professional advocacy with societies

- Families cannot afford CI services**
- Many appointments, varying test batteries among professionals/specialists
 - Affordability of OOP expenses to cover appts
 - Many families on high deductible or high co-pay insurance plans
 - Creates family issues (fear of job loss)

Lack of funding

Misinformation on CI

- Misinformation on surgery**
- Conflicting/negative messaging Procedure is misunderstood
 - Not "brain surgery"
 - Concern over reliability of CI
 - Lack of understanding on timing & outcomes
 - Earlier is better

- Fear/Uncertainty**
- Access to future treatments i.e. pharma, gene therapy
 - Societal Status- cosmetics more noticeable than HA
 - COVID concerns
 - Limited parent-to-parent support
 - Fear about immigration status
 - CI evals in the appropriate language

Fear of surgery

CI-PATH Pediatric Initiative Final Counter Measures and Working Groups

CI:PATH initiated an 'A3 Blueprint' to transform hearing healthcare

The Problem: Almost all children in the US receive newborn hearing screening. According to the CDC, in the US, approximately 1/1000 children are born with profound hearing loss (HL) annually and up to 2-3/1000 with moderate to severe or greater hearing loss. Despite the established evidence on the benefit of cochlear implants in children:

~50% US penetration rate among eligible patients

~90% Penetration rate in Australia, NZ, UK

The Goal: Every parent of a child with severe to profound hearing loss in the US will have timely referral and accurate information about CI required to make an informed decision about their child's hearing.

The Cause

- COMPLEX PROCESS:** Unclear referral criteria and coordination between specialized hearing care professionals
- LACK OF AWARENESS:** Poor communication of the importance of hearing on brain development
- LACK OF TIMELY REFERRALS:** Lack of simple, consistent metric to base referrals for CI and to include in professional training programs
- ECONOMICS:** Low professional advocacy for adequate reimbursement

The Counter Measures

- Establish a **simple referral criteria and standard test battery** across pediatric hearing care professionals on which to base appropriate recommendations for treatment
- Define and amplify **consistent, fact-based information** on CI backed by testimonials and scientific evidence
- Develop **training programs** for hearing and primary care professionals based on simple referral criteria

CI-PATH Working Groups

Counter measure #1 - Establish a simple referral criteria and standard test battery across pediatric hearing care professionals on which to base appropriate recommendations for treatment	Counter measure #2 - Define and amplify consistent, fact-based messages on CI backed by testimonials and scientific evidence.	Counter measure #3 - Develop training programs for hearing and primary care professionals based on simple referral criteria.
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CI-PATH Working Group Tactics

1

Counter measure

- Multi-center effort to establish a pediatric referral criteria
- Publication of referral criteria
- Embed into training programs and curriculums

2

Counter measure

- Delphi process to create evidence-based statements to inform caregivers of CI candidacy and benefits
- Develop content demonstrating outcomes.
- Dissemination of information on CI to target audiences.

3

Counter measure

- Survey recent AuD graduates
- Survey of pediatric audiologists
- Publication of survey data
- Curriculum developed to share with AuD programs

Interested in Supporting the CI-PATH?

Contact Jace Wolfe: jwolfe@oberketterfoundation.org



WE WANT YOU!

Shoot for the Moon!



- See you soon!