

Message Banking™ vs. Voice Banking: A Very Successful Proactive Model for People with ALS/MND



**14th Annual Allied Professionals Forum
Liffey Hall A | Convention Centre Dublin |
6 December 2016**



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“Our voice is our ACOUSTICAL fingerprint”



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History

- Introduced concept of and term ‘message banking’TM to the field in 1994 in a pediatric intensive care unit setting
- Applied the same principles to pediatric degenerative conditions in outpatient augmentative communication program
- At request of adult providers in community, started to work with people with ALS/MND and immediately applied and expanded message banking model for people with ALS/MND

First: definition

DEFINITIONS:

***Voice Banking** is a process of recording a large inventory of your speech that is then used to create a synthetic voice that approximates your natural voice.*

Done successfully, this would allow one to spell and create unique messages and then speak them through a synthesizer that approximates one's natural speech. There are now several options (both free and fee based) to create a voice.



Message BankingTM with your own

***voice** digitally record and store words, phrases, sentences, personally meaningful sounds and/or stories using your natural voice, inflection and intonation.*

These messages are catalogued as .wav files and may then be linked to messages in a variety of augmentative communication technologies or sound storage files. This will allow you to ‘retrieve’ a message and speak it in your own voice but does not allow you to create novel messages by spelling. If you have recorded individual words, you may combine those words to create unique messages, although the output will sound more staccato than your natural speaking.



Message Banking by proxyTM is the election of a proxy voice to do all recordings because issues of fatigue, pain or intelligibility may make it difficult for an individual to bank all messages. In this case, the patient may still bank ‘*legacy messages*’ but the majority will be banked by proxy.



TERMINOLOGY:

Legacy Messages are those messages, often delivered with unique intonation and prosody that are unique or particular to you. It may be a ‘trademark’ message you say or it may be a trademark *delivery* of a message that many people say. A legacy message does not need to be meaningful to the general population instead it may have unique and personal meaning to only you and a loved one. Further, a legacy message does not need to be real words to be meaningful. It may be the way you clear your throat in a sarcastic manner to communicate “*I told you so*” or it might be the invented pet name you have for a loved one delivered with your unique voice, intonation and prosody. Similarly, legacy message may be that stereotypical thing you say after your favorite sports team scores or it may be a unique greeting you deliver to friends. Those close to you may be helpful with identifying these *Legacy Messages* because sometimes they are so naturally part of socially relating with others, you may not even be aware you are ‘known’ for them.

Costello, j.m. 2011



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Nancy



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- set at 16/44 baud rate
- Must use wind guard
- Hold close to mouth for best quality
- Practice timing of push - speak – push



Strategy:

- **STRONGLY** discourage recording when sitting in front of computer in isolation
- **OVERWHELMINGLY** the success people have is based on real time banking in the authentic moment

To date:

- 175 people with ALS have message banked through our program
- Message banking initiated as soon as four days after official diagnosis with average of three months.
- People message bank at will throughout the day using portable recording devices for 1 – 17 months with an average of four months.

To date:

- Banked message totals range from 122 to 3075*
 - People did not always choose to use all of their banked messages.
- Banked messages have been incorporated into technology on tablets, technology using head mouse, switch access and technology using eye tracking. technology for 47 people to date
- For four people banked messages originally incorporated into hand held tablets and later into technology controlled with eyes or head mouse

Samples from our “impact on quality of life” reports/initial data

- Patients report:
 - message banking is the only hopeful activity through the course of the disease
 - People with ALS have reported having a ‘new reason for living’ when their banked messages are incorporated into speech generating technology

From: Nancy <[nancy](#)>
Date: Monday, August 8, 2016 12:56 PM
To: John Costello <john.costello@childrens.harvard.edu>
Cc: "[gre](#)"
Subject: update

It is no exaggeration to say talking in my own banked messages with this board makes me want to live!

I sang Happy Birthday to my one year old grandchildren on Saturday. I cracked some hysterical jokes.

I made my husband weep for joy on our anniversary.

It works well enough outside at church. Here I mostly say I love you over and over.

Keep up the good work,

Nancy



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<https://www.bostonglobe.com/business/2015/12/14/the-joy-hearing-morning-babe-even-after-als-robs-speech/wLDF1tMvByyWFFYxATq6RJ/story.html>



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“It’s very easy to lose sight of the person that I used to be, but with the message banking, it allows us to hold on to that.”

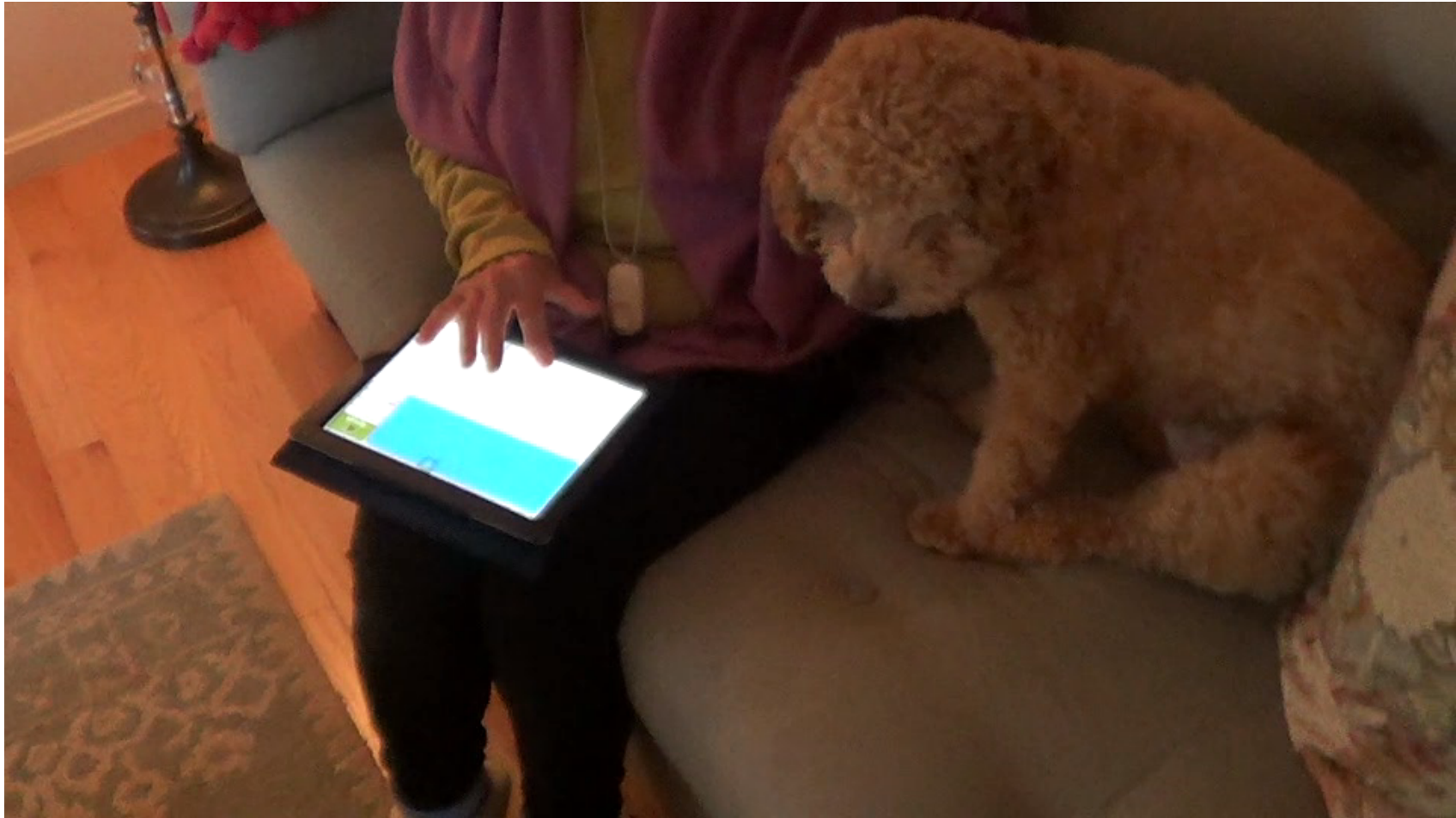
- Todd Quinn, Message Bank participant, diagnosed with ALS 2011



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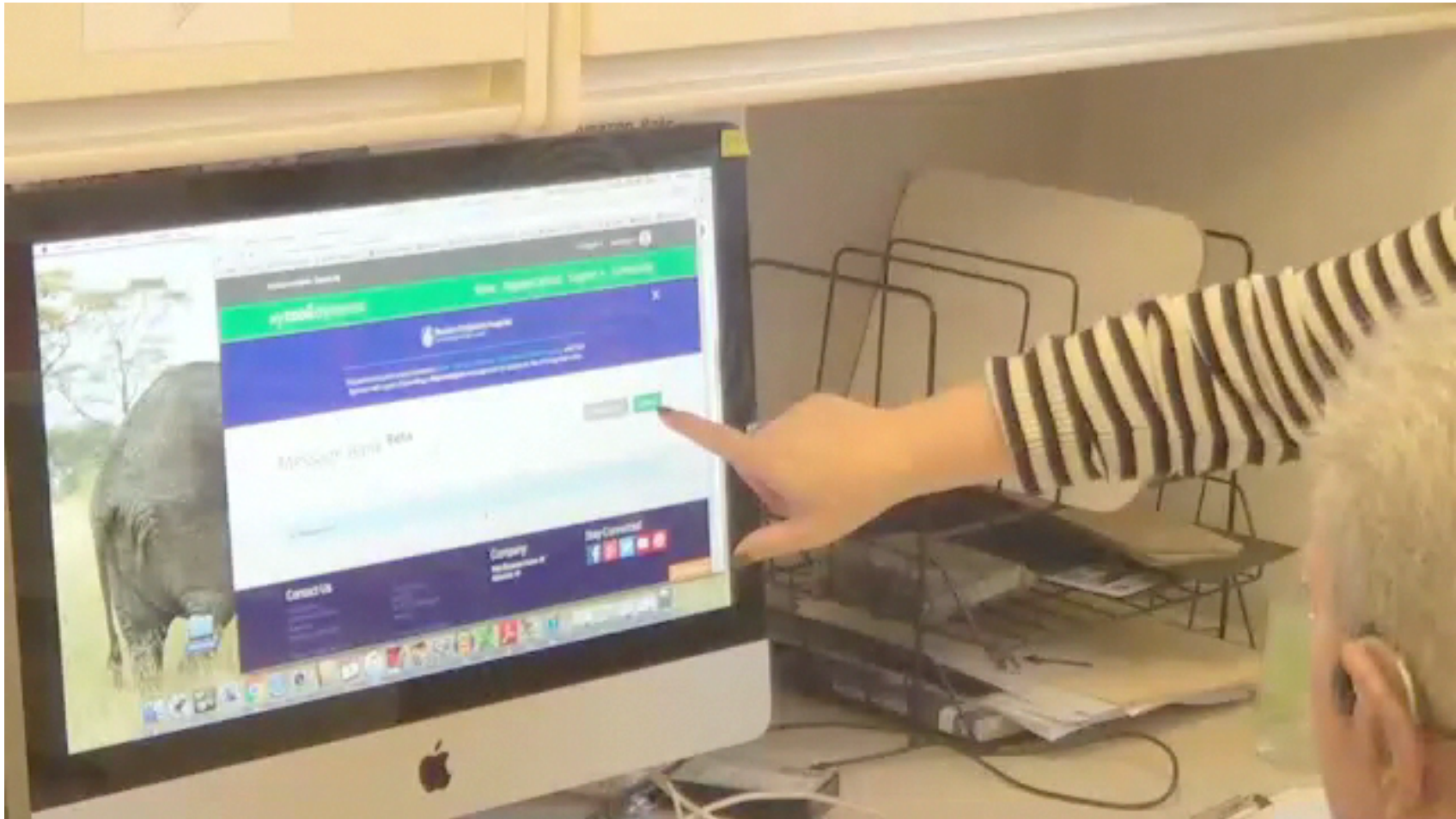


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Mr. D. using new FREE website



Collaboration with TobiiDynavox to create TECHNOLOGY AGNOSTIC and FREE message bank site hosted on the MyTobiiDynavox website

mytobii dynavox

Store Pageset Central Support Community

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This service is a joint project between Boston Children's Hospital Department of Otolaryngology and Tobii Dynavox with a goal of providing a **free and open** message bank for people at risk of losing their voice.

Message Bank

Upload

No messages found.



MESSAGE BANKING™ FOR EVERYONE

“After all, communication is the thread that connects us all.”

– John Costello, MA, CCC-SLP
Director at Boston Children’s Hospital and Creator of Message Banking



Message Banking is a joint beta project between Boston Children’s Hospital Department of Otolaryngology and Tobii Dynavox with a goal of providing a free and open message bank for people at risk of losing their voice.



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PLEASE CITE WORK AS:

Message Banking, Voice Banking and Legacy Messages
John M. Costello
Boston Children's Hospital
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DEFINITIONS:

Voice Banking is a process of recording a large inventory of your speech that is then used to create a synthetic voice that approximates your natural voice.

Done successfully, this would allow one to spell and create unique messages and then speak them through a synthesizer that approximates one's natural speech. The science behind this process continues to be in development with beta-versions of available software. The ModelTalker is one such project from the University of Delaware Speech Research Lab. The website is: www.asel.udel.edu/speech/ModelTalker.html



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Message Banking examples from people with ALS © 2014

Currently: 64 page
Message bank handout



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voice digitally record and store words, phrases, sentences, personally meaningful sounds and/or stories using your natural voice, inflection and intonation.

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THE VOCABULARY:

The following vocabulary was message banked by people with ALS. People graciously permitted us to share their messages and we attempted to organize the vocabulary by categories for ease of reference. [This list is NOT intended to be a page from which you can record.](#) It is intended to give people **ideas** of messages that others thought were important.

EXPRESSIONS

Idioms

- It's not my cup of tea
- Just the way it is
- Off the deep end
- Close to the moon
- Out of the blue
- Practice makes perfect
- That's the way the cookie crumbles
- You missed the boat

Social Requests

- Come talk with me
- I want a hug
- I need a kiss
- Do you feel I have an appointment now?
- Leave me alone
- May I go with you?
- Oh how love with me
- Would you like to go with me?
- You'll have to go.



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Message Banking examples from people with ALS © 2014



Humor

- Is that your real name?
- Items / messages to which I'd like to refer
- That one like when machine talking, normal?
- That's easy for you to say!
- Who programmed this robot/math?

Expressions of feelings

- Angry
- Better
- Feeling
- Frightened
- Frustrated
- Good!
- Happy
- Lovely
- Mad
- OK
- Overwhelmed
- Sad
- Shy
- Tired
- Worried
- Worse

Time of Day Based Expressions

- Did you have a good night's sleep?
- Good morning
- Good night, I hope you sleep well
- Good night, I love you
- Have a good day
- How was your this morning?
- How is your day going so far?
- It's like a morning walk
- I'd like to eat breakfast
- I'd like to eat dinner



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Message Banking examples from people with ALS © 2014



- I'd like to eat lunch
- I'd like to watch the evening news
- It's time for bed
- Please! Please!
- What time is it?
- When are they coming?

64 page handout will be on new ALS website but
can be found now as the first comment under the
announcement of USSAAC webinar on Message

Banking

(dated 11.9.17)

on our clinic facebook page:

[https://www.facebook.com/](https://www.facebook.com/ACPCHBoston/)

[ACPCHBoston/](https://www.facebook.com/ACPCHBoston/)



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