



**UNIQUE COMEDY
STORYTELLER**

LIVING WITH USHER SYNDROME

CANE

From Enemy to Friend

Boston Gardens

Old Town Alexandria



LIVING WITH USHER SYNDROME

SSP

“TOUCH DOWN” FOR THE DEAFBLIND



HELLO DOCTOR
HELLO RESEARCHER

MY NAME IS RENE

MESSAGE TO THE MEDICAL COMMUNITY

SEE THOSE WITH USHER SYNDROME AS MORE
THAN A MUTANT GENE

MY EXPERIENCE

RESULT?: DISENGAGED

WE NEED EACH OTHER

- START FROM THE CONSUMER'S PERSPECTIVE
- PARTNER WITH THOSE WITH USHER SYNDROME AND THEIR FAMILIES
- KEEP US ENGAGED THROUGH RESPECT AND REALISTIC HOPE

WE NEED EACH OTHER

RECOGNIZE THE VALUE OF THE DEAF
COMMUNITY AND SIGNED LANGUAGES

LET US TEACH YOU WHAT WE NEED AND VALUE

REACH OUT AND TOUCH SOMEONE(Hearing-
ear; Deaf-eye; DeafBlind-TOUCH)

WE NEED EACH OTHER

IF THE “CURE” DOES NOT
COME, WE ARE STILL HERE
AND WE CAN HAVE A GOOD
LIFE

REMEMBER THE “US” IN USHER SYNDROME

Each person with Usher Syndrome has
the power to bring together the
masses

BREAKING DOWN SILOS

WHO'S IN OUR WORLD?

- Parents and extended family
- Children and Grandchildren
- Friends and Neighbors
- Co-Workers

WHO'S IN OUR WORLD?

- Primary Care Physicians
- Audiologists
- Otolaryngologists
- Ophthalmologists

WHO'S IN OUR WORLD?

- Assistive Technology Specialists
- Orientation and Mobility
- Associations of the Deaf
- Associations of the Blind

WHO'S IN OUR WORLD

- Associations of the DeafBlind
- Interpreters
- CART Professionals(and Typewell/C-Print)
- Special Educators

WHO'S IN OUR WORLD?

- Support Service Providers(SSPs)
- Legislators
- **YOU!**

BREAKING DOWN THE SILOS

THANK YOU MARK DUNNING

**.....THE BEGINNING OF A
BEAUTIFUL RELATIONSHIP.....**

THANK YOU!



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