

Deafblind Library Collection

Usher Syndrome

Art of The Eye: An Exhibition on Vision

FORECAST

1986 Book

A collection of paintings, photographs and sculpture with essays by the artists about their own visual impairments. At least one artist highlighted, has Usher Syndrome. 96pp.

Business of Living with Retinitis Pigmentosa, "Stress and Well Being"

Stiefel, D.

1987 Book

This booklet is an attempt to offer ways to deal with stress, especially for individuals who have R.P. It is also for those with R.P. who want to feel their very best emotionally, mentally and physically. It is written by a woman with Usher Syndrome II. A personal account of Retinitis Pigmentosa 33pp.

Business of Living with Retinitis Pigmentosa, The "Dealing with the Threat of Loss"

Stiefel, D.

1982 Book

This booklet is an overview about the process of emotional entanglements while a person with R.P. tries to rally, recoup & reorganize; in essence, survive. Written by a woman with Usher Syndrome II. 21pp.

Deaf-Blind: Communication and Community, Getting Involved: A Conversation

Smith, T.

Sign Media, Inc.

1992 Video

This ninety minute tape offers two presentations of a forty-five minute conversation with Pat Cave and Janice Adams, two DeafBlind individuals. Moderated by Theresa Smith, this tape presents a fascinating discussion of topics such as general perceptions and experiences as DeafBlind adults and their communication frustrations and needs.

DeafBlind: Communication and Community: Overview and Introduction

Smith, T.

Sign Media, Inc.

1992 Video

This open-captioned tape features Theresa Smith discussing a number of topics that provide a glimpse into the multi-faceted Deaf-Blind community. Among the topics discussed are a definition and description of the community, individual communicative differences and preferences, becoming involved in the community, and setting limits. 40 min.

Usher Syndrome

Faces Of Success

Minnesota DeafBlind Technical Assistance Project

2001 Video

A video montage of four students with combined vision & hearing loss. Miles-7 years/meningitis; Kevin-12 years/CHARGE Syndrome; Jamie-19 years/Usher Syndrome II; Andrew-18 years/CHARGE Syndrome. 10 min.

Madness of Usher's, Coping with Vision and Hearing Loss (Usher Syndrome Type II)

Steifel, D.

1991 Book

The author says, "This book has a direct, two-fold purpose: First, to alert early in life, those persons who have hearing loss combined with R.P. and who may have Usher Syndrome Type II; and second, to all who desire to be informed. I draw intimate attention to a pervading kind of anguish and confusion that disrupts normal behavior." 78pp.

Nebraska Usher Syndrome Screening Project

Coonts, T.

Nebraska DeafBlind Project

2002 Book

This manual and forms packet was prepared to help school personnel in conducting screenings for Usher Syndrome. It provides information on what is Usher Syndrome, how to conduct a screening, the actual forms needed for a screening and state and national resources. 60 pp.

Orchid of The Bayou-A Deaf Woman Faces Blindness

Carroll C. & Fischer C.

Gallaudet University Press

2001 Book

This story is about the life of Kitty Fischer from the state of Louisiana. She discovered a high incidence of Usher Syndrome among Cajun people. Her lively story will entertain and speak to anyone who recognizes the arduous journey toward claiming an identity. 253pp.

Screening For Usher Syndrome; A hands-on guide for school nurses

Kansas Services for Children and Youth with Dual Sensory Impairments

1996 Book

Written specifically to help school nurses conduct screenings for Usher Syndrome, a genetic condition that involves hearing loss and progressive loss of vision. Step by step instructions. 55pp.

Usher Syndrome

Touching Lives: Portraits of DeafBlind People

Gordon, M. and Hajjar, S.

2002 Video

Depicts the remarkable lives, trials and triumphs of adults who are DeafBlind. Co-produced and narrated by Susan Hajjar, who has three siblings with Usher Syndrome. Close Captioned 56 min.

Understanding Usher Syndrome: An Introduction for School Counselors

DiPietro, L. (Ed.)

Helen Keller National Center

2002 Book

This book introduces basic information about the syndrome, stressing developmental and emotional issues that commonly arise for students and parents, to help them integrate this diagnosis into their lives. It also includes sections about the combined hearing and vision loss in Usher Syndrome and its effect on communication, career planning, and educational programming. Personal accounts by adults with Usher Syndrome and parents of children with Usher Syndrome provide first hand experiences. 144pp.

Usher Syndrome Conference, Tape 1: What is Usher Syndrome? and Characteristics and Screening. Improving Educational Services for Students with Usher Syndrome

Bohrman, J., Wynne, B.

2002 Video

Part 1: What is Usher Syndrome? Dr. Jeffrey Bohrman, Director of Ohio Deaf-Blind Outreach Program presents an overview of Usher Syndrome. He also explains the three types of Usher Syndrome. 11 min.

Part 2: Characteristics and Screening Sr. Bernadette Wynne from Helen Keller National Center gives an indepth presentation of the etiology of Usher Syndrome. Communication and psycho-social aspects are also presented. The audience participates in a simulated deaf blind experience activity with discussion following the activity. 84 min.

Usher Syndrome Conference, Tape 2: Panel Discussion; Improving Educational Services for Students with Usher Syndrome

Bohrman, J., Wynne, B.

2002 Video

This is a panel made up of four consumers who have Usher Syndrome. Each person shares his or her unique experiences living with Usher Syndrome. Among the panel members are those who have Usher Syndrome Type I and Usher Syndrome Type II. Panel members presented personal issues pertaining specifically to how they found out about Usher Syndrome, challenges, support services, and advice to professionals, teachers, and parents with children with Usher Syndrome. 50 min.

Usher Syndrome

Usher Syndrome Conference, Tape 3: Teaching Accomodations, Transition Supports and Accommodations; Improving Educational Services for Students with Usher Syndrome

Wynne, B.

2002 Video

Part 1 Sr. Bernadette Wynne provides techniques for making accommodations in the classroom including use of simple reading and writing aids for students with Usher Syndrome. She provides examples of accommodations used in communication taking into account limited field of vision, night vision, distance and tactile sign language. She also discusses some of the emotions persons may feel as their vision changes. The audience participates in a simulation activity to practice accommodating communication and discuss their experiences and observations.

Part 2 Transition Supports and Accommodations, Sr. Bernadette Wynne presents information about transition supports and making necessary accommodations. She shares how to have a better understanding of parent feelings. Feelings of students with Usher Syndrome are shared regarding transitioning from different methods of communication. 50 min.

Usher Syndrome Conference, Tape 4: Assistive Technology; Improving Educational Services for Students with Usher Syndrome

Bohrman, J.

2002 Video

Dr. Jeffrey Bohrman demonstrates various assistive technology used by people who are deafblind to enhance daily living. Some examples shown are personal alert systems, large print and refreshable braille TTYs. He demonstrates how these devices can be used for personal alarms, reading, telephone, and communication. Dr. Bohrman talks about computer programs used by people who are deafblind. He also gives the cost of the devices. 36 min.

Usher Syndrome in the School Setting

Miner, I. & Cioffi, J.

Helen Keller National Center T.A. Center

1997 Book

This monograph addressing Usher syndrome in the school environment is intended for high school students, teachers, support staff, vocational rehabilitation counselors, and family members. Topics in the book include: defining Usher syndrome, looking for signs, common experiences of people with Usher syndrome, Usher syndrome and the family, family and school interaction, orientation and mobility, vision assessment in the classroom environment, and next steps. 47 pp.

Usher's Syndrome: What it is, How to Cope and How to Help

Duncan E., Prickett H.T., Finkelstein D. Vernon M. & Hollingsworth T.

Charles C. Thomas Publishing Co.

1988 Book

This book contains six indepth interviews with individuals who have Usher Syndrome followed by discussions concerning medical aspects of Usher Syndrome: how to effectively communicate, psychological adjustment, employment and vocational rehabilitation, recreation and social interaction. 94pp.

Usher Syndrome

When Hearing Loss and Retinitis Pigmentosa Happen Together: Meeting Educational Needs

Raistrick, K. and McGann, R.

Pennsylvania DeafBlind Project

1996

Video