The following video scrolls through a series of slides of headshots of individuals, text, and crayon drawings. In all photos, the left side of the person’s face is in a shadow and the right side of the person’s face is visible in a soft white light Background of photos is dark gray. Soft circle of illumination is behind each person’s head. Instrumental music plays in the background. All text is white on dark background.

Transcript of “Shine a Light on Usher Syndrome. “

[Image: Point of white light shines in center of screen then fades to right as text comes on screen] Text: Shine A Light On Usher Syndrome

[Image: young boy, straight, dark brown hair, orange, blue and gray striped shirt, eye glasses with cord behind neck, hearing aid] Text: Usher syndrome is the most common genetic cause of combined deafness and blindness

[Image: young woman, long blond hair, blue button down shirt.] Text: More than 400,000 people are affected by this disorder worldwide

Text: What does Usher syndrome (USH) look like

[Image: young boy, blond hair, green sweatshirt, glasses, hearing aid]

[Image: man, dark brown hair, light blue collared shirt, dark rimmed glasses)

[Image: young woman, gray t-shirt, long blonde hair over left shoulder]

[Image: woman, white hair pulled back, blue denim top with decoration around neck, cane stands upright to her right] Text on screen: We are the faces of Usher syndrome

[Image: young boy, brown hair, red shirt, dark rimmed glasses, device over ear, sits with older boy, dark brown hair, orange shirt, dark rimmed glasses] Text: Our drawings are our voices

[Image: drawing of three figures in descending height order, all with short shorts and short sleeved shirts, black hair and glasses, holding hands in a straight line across page. A yellow crescent is in upper right side of drawing. All figures’ eyes look left towards words “A Cure.” Figure on far left of drawing points to words and has a speech bubble saying “We’re almost there.” Caption on bottom left of drawing says “USH KbK Art Party”]

[Image: young girl, curly brown bangs, hair pulled back, shirt with white straps and blue and white pattern] Text: We need people to be aware of this disease

[Image: young boy, short brown hair, blue hooded sweatshirt with emblem on front] Text: We are young

[Image: man, gray beard and mustache, cap on head, glasses, dark blue collared shirt.] Text: We are old

[Image: woman, long blond hair, white and pink shirt] Text: We are every age

[Image: woman, curly brown hair, plaid shirt, necklace.] Text: We need to raise awareness of USH so we can find a cure

[Image: woman, white hair pulled back in ponytail, blue sweater. Golden haired dog sits to her right] Text: Help Shine a Light on Usher Syndrome

[Image: young woman, brown shoulder length hair, white lace sleeveless shirt.] There is a light at the end of this dark tunnel

[Image: drawing of door outlined in yellow in middle of page. All around door colored black. Caption on bottom right says “USH KbK Art Party”]

[Image: woman, shoulder length wavy light brown hair, glasses, black sweater set. Black dog sits to her right.] Text: Before the darkness takes over our light

[Image: young boy, dark straight hair, plaid shirt] Text: And our world is left silent

Text: DONATE NOW Visit [www.kidzbkidz.org](http://www.kidzbkidz.org) to help fund the USH Trust Registry. For more information on Usher syndrome visit [www.usher-syndrome.org](http://www.usher-syndrome.org). Photos by Evan McGlinn. [Logos of Usher Syndrome Coalition and Kidz b Kidz]