HUNTINGTON’S DISEASE

IF YOU HAD A CRYSTAL BALL WOULD YOU LOOK INTO IT TO SEE YOUR HEALTH FUTURE? AT UC DAVIS MEDICAL CENTER THERE IS ONE PROGRAM DOING SOME REAL LIFE PREDICTING. AND IT INVOLVES A COMPLEX GENETIC DISEASE.

THE MIGHTY BRAIN, WE USE IT IN SO MANY DIFFERENT WAYS, IT CONTROLS MOTOR FUNCITIONING, HOW WE MOVE AND GROOVE OUR MUSCLES. THE BRAIN IS ALSO A THINKER. IT PROCESSES OUR EMOTIONS, ALLOWING US TO LAUGH OR CRY, YELL OR CHEER. BUT THERE IS A NEUROLOGICAL BRAIN DISEASE THAT CAN SEVERLY IMPACT HOW THE BRAIN FUNCTIONS.

Barbara Briscoe: "I think for most people if you describe it, and for people who get a new diagnosis in the family and they go look I up in a medical book, they are horrified, horrified to read the description of Huntingtons.”

HUNTINGTON’S DISEASE IS A PROGRESSIVE DISORDER THAT CAN SET IN ANYWHERE FROM ABOUT AGE TWENTY TO SEVENTY. IT’S A GENETIC CONDITION THAT IMPACTS THE BRAINS’ ABILITY TO CONTROL MOVEMENT, AND THE FIRST SIGN OF THE DISEASE IS OFTEN FIDGETING, MUSCLE TWITCHING OR RESTLESSNESS. THE DISEASE ALSO IMPACTS THE BRAINS ABILITY TO CONTROL THINKING AND EMOTIONS.

Dr. Wheelock: “Huntington’s Disease is a disease that runs in families and it has a pattern in families called autosomal dominance so that if a person who has it has children each of there children has a 50% chance of inheriting that abnormal gene.”

DR. VICKI WHEELOCK IS A NEUROLOGIST WHO SPECIALIZES IN HUNTINGTON’S DISEASE AT UC DAVIS MEDICAL CENTER. SHE IS COMBINING INNOVATIVE RESEARCH WITH A PROGRESSIVE TEAM APPROACH TO FIND ANSWERS ABOUT HUNTINGTON'S. SHE IS INVOLVED IN A STUDY WHERE PATIENTS THAT MAY HAVE THE GENE, BUT DON’T WANT TO KNOW IF THEY DO, ARE STUDIED FOR THREE YEARS. THE HOPE IS TO FIND OUT ABOUT THE VERY FIRST SYMPTOMS OF HUNTINGTON’S DISEASE.

Dr. Wheelock :“We can have some information about people who may develop that disease during that observation period that will enable us to better design trials of medication that may delay or ameliorate the effects of having the effects of having the abnormal gene.”

FOR PEOPLE WHO WANT TO KNOW THEIR HUNTINGTON GENE STATUS COMES IN MANY FORMS. THERE IS A PREDICTIVE TESTING PROGRAM THAT OFFERS A BLOOD TEST TO DETERMINE IF YOU HAVE THE GENE. MAKING THE DECISION TO FIND OUT OR NOT CAN BE A DIFFICULT

THING. HUNTINGTON'S DISEASE RUNS IN FAMILIES, BUT IN THE PAST LACK OF INFORMATION ABOUT THE DISEASE KEPT IT A MYSTERIOUS, DARK FAMILY SECRET. DR. WHEELOCK AND OTHER SPECIALISTS ARE TRYING HELP PEOPLE UNDERSTAND AND DEAL WITH THIS CONDITION.

Barbara Briscoe: "For some it's pretty clear and straight forward-they are concerned about their children and their grandchildren having children-not necessarily because they don't think they should-but they feel like they should have an opportunity to know what their risks are."

BARBARA BRISCOE IS A GENETICS COUNSELOR AT UC DAVIS MEDICAL CENTER, SHE WALKS PEOPLE THROUGH A GENETICS LESSON AND COUNSELING TO ASSIST THEM IN MAKING THE DECISION ABOUT GENETIC TESTING.

Barbara Briscoe: "I think the information is there, and I think it can be extremely helpful for people. Some people live their entire lives feeling like the time they dropped a glass or foot shaking is the onset of their disease and for them it can allow them to live a life free of that ambiguity which is, I think, emotionally difficult to live with."

Sally Klien: "People are pretty anxious, number one they're anxious to get through the process of testing and find out the results for themselves and for their family members. Number two they're anxious just coming to the UC Davis medical Center to this huge area and going through this process with individuals they don't know."

SALLY KLIEN, A CLINICAL NURSE SPECIALIST, IS ALSO PART OF THE TEAM HELPING THOSE AT RISK FOR HUNTINGTON'S. HER JOB IS TO DEAL WITH THE PSYCHOLOGICAL ASPECT OF THE CONDITION. SHE IS CONCERNED ABOUT HOW HUNTINGTON'S MAY BE AFFECTING THE PATIENT MENTALLY AND EMOTIONALLY AND WHY THE PATIENT WANTS TO KNOW IF HE OR SHE HAS THE GENE.

Sally Klien: "When we talk to the individual we go through the what ifs- what if you should test positive what would you do-what if you should test negative what would you do? Because we are concerned."

GENETIC COUNSELING, A PSYCHOLOGICAL ASSESSMENT AND PREDICTIVE TESTING ARE ALL A PART OF THIS PROGRAM. IT IS A UNIQUE APPROACH AND THE ONLY ONE IN NORTHERN CALIFORNIA.

Dr. Wheelock: "We actually specialize in the care of people with Huntington's disease and providing information to them and their families about the disease; treating the symptoms as best as we can; involving them in our research studies; letting them know about the support group; the predictive testing program that we have we let families know about it."

THERE IS NO CURE FOR HUNTINGTON'S DISEASE, BUT DR. WHEELOCK HOPES THE STUDY SHE'S INVOLVED WITH CAN OFFER AN ANSWER TO THIS COMPLEX CONDITION. THE GOAL OF THE HUNTINGTON PROGRAM IS TO OFFER THAT CRYSTAL BALL — GIVE PATIENTS INFORMATION IF THEY WANT IT — AND HELP THEM DEAL WITH WHAT THE TESTS REVEAL.

MANY PATIENTS AVOID GENETIC TESTING IN FEAR OF LOSING THEIR COVERAGE. BUT UC DAVIS MEDICAL CENTER KEEPS STRICT CONFIDENTIALITY ABOUT HUNTINGTON CASES. IT BELIEVES THAT THE RESULTS ARE IMPORTANT FOR THE PATIENTS FUTURE, AND THAT INFORMATION IS BEST KEPT BETWEEN THE PATIENT, HIS OR HER FAMILY, AND THE MEDICAL CENTER.