*Include 3 bullets (< 30 words total) per slide – the most important messages associated with the particular slide*

Team name: EPP Light Dosimeter

Date updated: 12/1/2019

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| S1: Title  & Elevator Pitch/Headline | * Title: Smartphone-based digital devices for quantitative disease monitoring in erythropoietic protoporphyria * Headline: If you’re like most people, you enjoy the sun, and you miss it if it’s gone for days or months at a time. But did you know that some people’s skin can’t tolerate sunlight? * improve quality of life and bring new therapies to patients |
| S2: The problem and who has it | * EPP 1:100,000, but multiple forms of photosensitivity. No biomarkers. * Prolonged, untreatable pain, decreased quality of life * Difficulty predicting and preventing symptoms * No precise endpoints for clinical trials |
| S3: The solution | * Digital biomarker * Measure the exposure, the symptoms, and the biochemical response with a light dosimeter, symptom survey, and a fluorescence spectrometer, respectively. * improve quality of life and provide quantitative endpoints for clinical trials |
| S4: Product (how it addresses the problem) | * The light dosimeter, SunSense, UV light exposure * The fluorescence spectrometer, Labby, skin fluorescence |
| S5: Technology | * A visible light sensor: measure visible light not just UV * A cutaneous spectrofluorometer: excitation and emission properties are specific for protoporphyrin. |
| S6:  Competing approaches | * For clinical trials in EPP: light exposure diaries. * The primary end point of the last trial completed in 2011 was the cumulative number of hours in direct sunlight between 10am and 6pm without pain over a period of 6 months. |
| S7:  Traction | * Spark Grant, the Porphyrias Consortium grant, HTL * SunSense and Labby. * American Porphyia Foundation trainee and starting a satellite site of the Porphyrias Consortium. |
| S8:  Team | * My supporting mentors at MGH are Irene Kochevar and David Christiani * I have mentorship through the IDEA2 program and the Healthcare Transformation Lab. |
| S9:  Closing | * **The goals:**guide patient exposure and quantitative endpoints for clinical trial data collection * **Ways this will help patients:** improve quality of life and facilitate the approval of new medications for EPP and other forms of photosensitivity |