

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

Team name: EPP Light Dosimeter

Date updated: 10/11/2019

S1: Title & Elevator Pitch/Headline	<ul style="list-style-type: none"> <li>Title: Smartphone-based digital devices for quantitative disease monitoring in erythropoietic protoporphyria</li> <li>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 some people's skin can't tolerate sunlight? Erythropoietic protoporphyria, or EPP, is a lifelong medical condition that causes painful sensitivity to light. I have EPP.</li> <li>My project will improve quality of life and bring new therapies to patients</li> </ul>
S2: The problem and who has it	<ul style="list-style-type: none"> <li>Prolonged, untreatable pain</li> <li>Decreased quality of life</li> <li>Difficulty predicting and preventing symptoms</li> <li>No precise endpoints for clinical trials</li> </ul>
S3: The solution	<ul style="list-style-type: none"> <li>Adapt and test technologies currently used for skin cancer</li> <li>Measure the exposure, the symptoms, and the biochemical response with a light dosimeter, symptom survey, and a fluorescence spectrometer, respectively.</li> <li>In the future, understanding this data will be able to guide patients symptoms and improve quality of life and provide quantitative endpoints for clinical trials, bringing new therapies to patients.</li> </ul>
S4: Product (how it addresses the problem)	<ul style="list-style-type: none"> <li>The light dosimeter was designed by SunSense and measures visible light exposure</li> <li>The fluorescence spectrometer was designed by Labby and measured the amount of a fluorescence biomarker in the skin called protoporphyrin</li> </ul>
S5: Technology	<ul style="list-style-type: none"> <li>A visible light sensor was added to a smartphone-based wearable light dosimeter that already measures UV light.</li> <li>A cutaneous smartphone-based spectrofluorometer was designed for skin screening. This was adapted so that the excitation and emission properties are specific for protoporphyrin.</li> </ul>
S6: Competing approaches	<ul style="list-style-type: none"> <li>There currently exists no method for patients to monitor exposure and predict their symptoms.</li> <li>For clinical trials in EPP, these have used a light exposure diaries.</li> <li>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.</li> </ul>
S7: Traction	<ul style="list-style-type: none"> <li>In addition to the Spark Grant, the Porphyrins Consortium was able to receive renewed funding for their U54 grant. Though not directly for this project only, I'll be getting a part-time clinical coordinator through that.</li> <li>I have Partnerships through SunSense and Labby.</li> <li>I am doing a healthcare innovation fellowship through the Healthcare Transformation Lab at MGH. I also am a trainee of the American Porphyrin Foundation and a satellite site of the Porphyrins Consortium.</li> </ul>
S8: Team	<ul style="list-style-type: none"> <li>My supporting mentors at MGH are Irene Kochevar and David Christiani</li> <li>I have mentorship through the IDEA2 program and the Healthcare Transformation Lab.</li> </ul>
S9: Closing	<ul style="list-style-type: none"> <li><b>The goals:</b> <u>guide patient exposure</u> and <u>quantitative endpoints</u> for clinical trial data collection</li> <li><b>Ways this will help patients:</b> <u>improve quality of life</u> and facilitate the approval of <u>new medications</u> for EPP and other forms of photosensitivity</li> </ul>