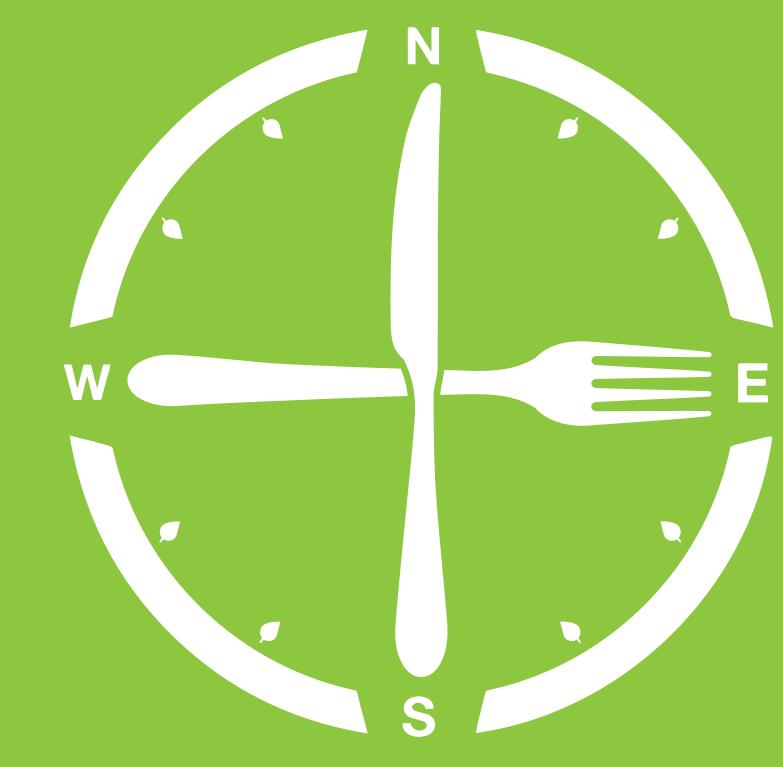


NAVIGATING A LIFELONG FOOD DESERT

How a Low-Protein Grocery & Restaurant Locator App Gives One Rare Community a Tool to Help Itself



GOLOWPRO

INTRODUCTION

The low-protein diet for Phenylketonuria (PKU) and similar inborn errors of metabolism (IEMs) is restrictive, inconvenient, and time-consuming to maintain. Exceeding your dietary protein Rx can severely impact your health, with effects ranging from increased anxiety and deficits in concentration and executive functioning, to seizures, coma, and permanent brain damage, depending on diagnosis. Parents and caregivers manage the diets for most children. Teens, young adults, and those in the workforce and with families have less support and more responsibilities, and are at higher risk of “falling off diet.” This can lead to a devastating and unhealthy cycle; even mild symptoms can compromise the skills needed to plan, cook, calculate, track, and advocate for one’s diet.

METHODOLOGY

IN PERSON:

We conducted an interactive forum with young adults, their caretakers, and adults with PKU to identify the largest barriers to staying on diet

ONLINE:

We analyzed 1 year of social media posts on low-protein foods and dining

RESULTS

FOCUS GROUP SUMMARY:

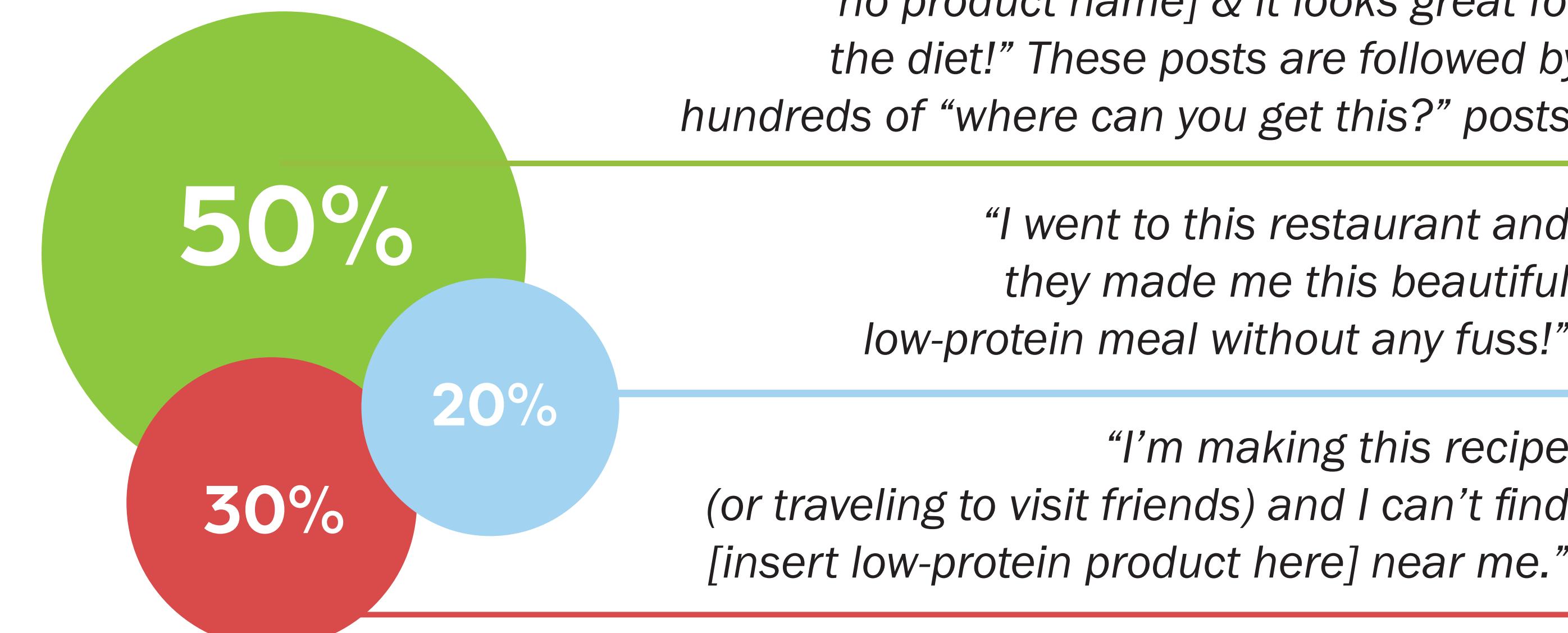
Young adults reported that increased freedom and time on their own meant:

- With less guidance from caretakers, they struggle to make healthy choices
- They don't know where to find diet-appropriate meals when out with friends
- They face increased peer pressure which makes dietary compliance harder
- They have difficulty adjusting to new circumstances (like college) without knowing where to find low-protein groceries and meal options

Adults with families and/or jobs reported:

- Less time to search for and shop for specialized groceries, and prep meals
- Discomfort in professional situations like dining with coworkers
- Difficulty traveling for work or leisure because they don't know what low-protein resources will be available at their destination

SOCIAL MEDIA SURVEY:



CONCLUSIONS

SOCIAL MEDIA IS A BAD WAY TO TRY TO MEET THIS COMMUNITY'S DIETARY NEEDS BECAUSE:

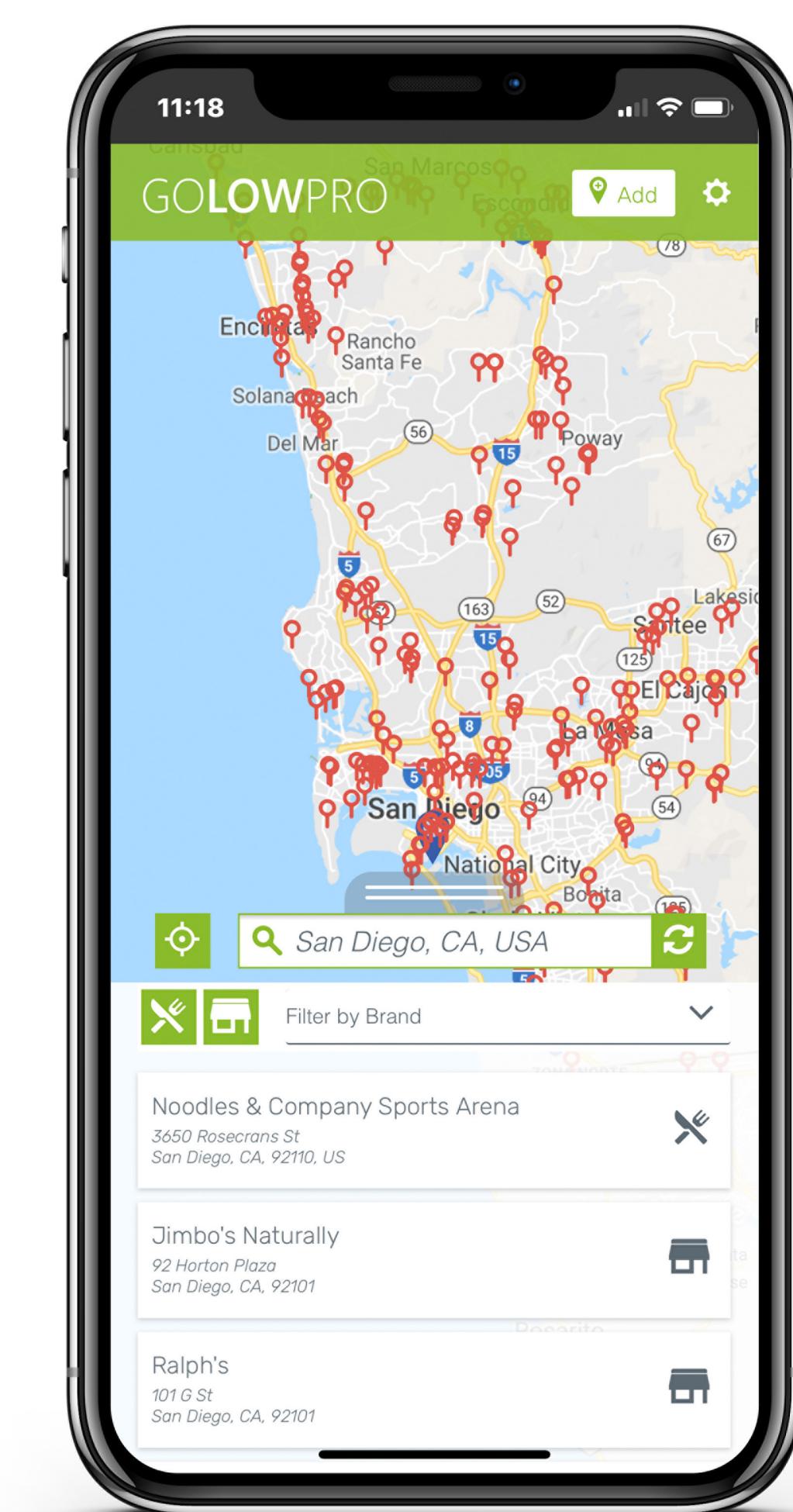
- WHERE ARE YOU?** Products/restaurants are specific to the original poster's location, which is often unknown.
- DISEASE COMMUNITIES ARE SILOED:** Social media centers around disorders, not treatments.
- CONTENT IS DISTRIBUTED** across dozens of Facebook groups, Twitter, and Instagram Feeds. No way to consolidate or track.
- TIME PASSES** and the feed moves on. No way to index or search.

The current methods for locating groceries & restaurants suitable for the low-protein diet for IEMs are inadequate and this affects patients' health. Teens & adults are at higher risk and need a better way to access this info, compatible with their more independent and active lifestyles.

TO MEET THE NEEDS OF THIS AT-RISK COMMUNITY NATIONAL PKU NEWS CREATED GO LOW PRO

Download on the
App Store

GET IT ON
Google Play



FOCUSED ON YOU

Uses your phone's built-in geolocation to find stores and restaurants near you

PRE-LOADED WITH FAVORITES

Seeded with brands and chains that work with the low-protein diet

POWERED BY YOU

Users can add brands, products, stores, and restaurants—with photos & reviews—that are compatible with the low-protein diet

READY TO TRAVEL

Enter a city/state or postal code to find locations near your destination. US & Canada at launch. Worldwide support in 2020

DESIGNED TO MEET YOUR NEEDS

Built with input from the low-protein community, who requested these features:

- Search by brand
- Filter to see stores, restaurants, or both
- Find locations based on featured searches (e.g. pizza or cooking staples)
- Save your favorite locations to your account for easy access and repeat visits
- Easily click through to brands in HowMuchPhe.org
- View the protein tolerance of those who recommend restaurants to evaluate if it will work for your diet

BRINGS COMMUNITIES TOGETHER

Leverages the input of thousands on a low-pro diet to create a stronger resource for us all

ACKNOWLEDGMENTS



GOLOWPRO
IS A PROJECT OF

Support for the development of GO LOW PRO was provided by a grant from the Innovation Fund of the Global Genes' Rare Patient Impact Grant Program. Additional funding was provided by MACPAD, The Michaux Family Foundation for PKU, NECPAD, & the Tennessee PKU Foundation.

NATIONAL
PKU News

