

# COMMUNITY LED FUNDRAISING

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UK

Advocacy Session #  
Best practice in patient advocacy  
#MPNHZ22



***Fundraising for a small niche charity  
Involving and helping the whole community***

- ***We would not exist without fundraising, donations and grants***
- *We do not have the same infrastructure as the large charities*
- *We rely on family and friends to help where our patients cannot*
- *We have a real split of ability due to age and ability\*(due to health)*
- *We have to rely on the traditional activity for sponsorship*
- *We know that people will always support us purchasing merchandise that is either useful or seasonal, but fulfillment is never easy*

## *How to fundraise in the community in the most inclusive ways*

- *Walk in the shoes of those you are trying to help*
- *Physical, non physical. Adapt to include all*
- *Don't complicate - Keep the message simple*
- *How to best communicate*
- *Keep asking*
- *Look for new, innovative and relevant ideas*

## ***How to fundraise in the community in the most inclusive ways***


- *We continue to offer supported places to major charity sporting events that are donated to us in limited numbers*
- *We support the community's own initiatives which are always fun and creative*
- *We launched our first "Walk to Support Campaign"*
  - ✓ *Open to all patients, family, friends and anyone wanting to help us, wherever in the world you are*
  - ✓ *Choose your own place/route to participate*
  - ✓ *Choose a distance to suit your ability*
  - ✓ *5km, 10km, 20km, You can do this is over a day or over a week*
  - ✓ *Walk with a pet, family, friends, on your own*
- *We had a lot of interest and a good take up following a regular social media campaign including patient pictures and several email shots*

## ***Recipe Book Idea***

- *Patient idea to produce after studying the benefits of healthy lifestyle, both fitness and diet*
- *We knew we couldn't do this alone*
- *Engaging professionals was financially prohibitive*
- *The community have lots of skills and excelled*
- *We asked for help in sending in favourite healthy recipes*
- *Alice wrote a foreword regarding her inspiration, her mother gave her experience on the effects of the diet change*
- *A patient wrote a poem, another wrote of their experience with diet*
- *The clinicians provided the latest information on MPNs*
- *Nutritionists gave sound advice on healthy lifestyle and diet*
- *MPN Voice was able to inform on the services and support offered*
- *A support tool put together for the community, by the community*

HYBRID MEETING • NETANYA • ISRAEL • 18.-20.11.2022.

*We now have a book which is a fantastic support tool for patients,  
family and friends*




[www.mpnvoice.org.uk](http://www.mpnvoice.org.uk)

MPN Voice provides support to patients and their families across the world who have been diagnosed with rare blood cancers called Myeloproliferative Neoplasms. The chronic nature of these diseases means that it is very important for those affected to maintain a healthy lifestyle and look after their general wellbeing. Nutrition plays a key role and recent research suggests that following a healthy, Mediterranean-style diet can help reduce inflammation in MPN patients, reducing symptoms and potentially changing future disease trajectories for the better.


This recipe book is inspired by this work and brings together some of our community's favourite dishes. You'll find recipes ranging from Mediterranean pastas and salads to stuffed peppers and lentil soups. Each of the recipes has a personal touch, featuring the name of the patient who kindly submitted it to the charity and occasionally, the story behind it. This book offers you the chance to make some of these dishes at home and try ingredients you may not normally cook with.

For many people, cooking is a form of relaxation and therapy which allows the everyday stresses and strains of work and office life to melt away. Food also has the power to bring people together, providing an opportunity to sit down with friends and family, and connect with others over a shared meal.


We hope this recipe book, which has been curated by the MPN community for the MPN community, will offer you new recipe ideas and help those who may be thinking about changing their diet, but aren't sure where to begin. By purchasing the book, you will be making a valuable contribution to MPN Voice and its vital work in supporting people with rare blood cancers.



ISBN 97884886274  
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## The MPN VOICE RECIPE BOOK





## ***Conclusion and recommendation:***

- *Reach out to your community and utilise the skill sets you have available to you. There is lots of talent to call on.*
- *People want to help in ways that they are very able to do. Embrace every opportunity you can.*
- *Celebrate all the success and preparation with the community with permission on social media. These posts often get the biggest reactions.*
- *Make your idea happen, you will have hurdles and you will need to tread in unknown territory.*
- *Together we can achieve anything!*

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