We are interested in helping assess what can be done to combat the effect of the accumulator insurance co-pay “surprise”, particularly if it negatively affects access to care and the quality of life for those living with AiArthritis diseases. We requested a grant in the amount of $7,500 from Pfizer to investigate current efforts to address this situation, in an attempt to:

1. Assess what patients already know about the accumulator issue (if anything);
2. Who is being affected most;
3. What current groups are doing to address this problem (we do not duplicate efforts);
4. Identify gaps in existing efforts, if any, that we could address to help solve the problem.

Process and Results

1. **Online discussions.** After a series of online conversations with over 5 dozen individuals, we concluded:
   a. None of the patients who claimed this was happening to them actually had this happening to them. After follow up (direct messaging and one on one discussions), we determined they were experiencing step therapy, not accumulator issues.
   b. When asked, “Regardless of what the reason may be, imagine you were unable to fill your biologic medication for several months. How would this affect your life?” the responses were all dire, including: “I would cry”; “I would not be able to function”. When specifically asked if a person who worked could continue to do so, 100% stated “no”. **We believe this conversation should continue in order to gain the reality of what COULD happen IF the accumulator occurred, rather than attempt to collect stories from people who have already had it happen – as we could not identify anyone (see a).**

2. After **literature assessment**, existing policy, and educational materials published by other nonprofits and stakeholders, it is clear the two groups most affected are:
a. Those using employer sponsored plans.

b. Those with high-deductible plans.

3. **Current initiatives.** We identified several publications (posters, power points, website pages, etc.) created by nonprofits and other stakeholder groups (NORD, iFPA, Arthritis Foundation, Global Healthy Living Foundation/GHLF) that are educating patients about this issue. **We will not replicate those efforts. Therefore, we will not be doing any type of posters or publications educating patients, rather we will refer our community to those resources. We did feel GHLF had a very robust site that covered many facets of patient education, including a hot line for both patients or employers to call with questions. We did, however, identify ONE area that was missing from their site (see #4).**

We also identified a piece written by Abbie that addressed employers.

“Employers should consider the big picture What if the employee couldn’t afford that expense in April? What would be the outcome if he simply stopped taking his medication? Perhaps he would end up at the emergency room or require an inpatient hospitalization. What would these health care services cost the employer? Don’t force your members to face a “co-pay surprise.” Consider the unintended consequences that may be the end product of an accumulator adjuster program.” It also provided examples what an employer could do. **What was missing was the heart and soul behind the “what if this happens to me.”**

4. Identifying gaps. After all literature review, we conducted a brainstorming session to connect the dots and perform a final
Gap Analysis – Brainstorming Activity

- *Given most nonprofits are already addressing patient education, and what to do if you have a high-deductible plan, we feel the missing audience is the patient who has the EMPLOYER SPONSORED PLAN.*
- As mentioned in #3, AbbVie has addressed this from the Human Resources (HR) business angle (necessary), but what is missing from their approach is the “heart and soul”. The stories from their employees what would happen IF they were forced to work without their medication. Examples include:
  a. *Pain, inability to do regular tasks, may not be able to be at work for same duration, more doctors’ visits, more days off*
  b. *Brain fog, inability to think clearly, complete tasks*
  c. *Late for work (stiffness)*
  d. *Need for remote office accommodations and in office accommodation*

  *Think stories just like for the Hill in D.C. These same stories could even be used for legislative purposes.*

- Whatever is discussed with HR department, costs are still their top priority, and this must be considered in the conversation, paralleling the patient stories “heart” and realities.

5. Solution

*Overall, the missing gap identified is to target EMPLOYERS with STORIES that address the FUTURE IMPACT of accumulator – what their decision will cause to their staff. “THIS IS WHAT WILL HAPPEN TO YOUR EMPLOYEES IF YOU CHOOSE TO DO THIS”.*

*Once we find these (stories and surveys/hard data), we use this to launch both a strong social media campaign to recruit more patients who are employed and who can relate to this to join the fight AND we unite several nonprofits to create a campaign targeting HR/employers. This could be along with pharma, who could provide some of the necessary business statistics – like in the AbbVie report.*
6. Next Steps

- Start hosting online conversations and surveys to collect stories from employed patients to determine what life would be like if they suddenly did not have access to their medications. What would this mean for employers? We will create a basic infographic from this data.
- This work should fit in with existing efforts as a supplement to benefit work of others in our community; it will not duplicate anything any other organization is doing.
- **For a next leg of this project**, IFAA would like to team with other group(s)/new proposal to launch a social media campaign to recruit more patients who work, and develop a presentation to employers and HR staff, perhaps in conjunction with reports like done by AbbVie, so they understand the realities of what COULD happen if they enforced the accumulator on their staff with AiArthritis diseases.