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Post-Polio Clinics Directors Network
August 17, 2004

Disclaimer: The following are unofficial notes which have not been read by or approved by the speaker.

Presentation/Discussion:

Dr. Vandenakker's interest in this subject stems from the fact that a number of post-polio patients may not be using statin drugs because of concern about muscle weakness and fatigue.

Her case presentation is on a 60-year-old man who came for a post-polio evaluation with the usual complaints of progressive weakness and fatigue especially in the polio leg. He had heart problems and at that point was on Lipitor®, 10 ml a day, in addition to other medications. He is a well-educated man, a Ph.D, lobbyist for the legislature, ambulatory and did a little exercise. He had a lot of muscle pain and was concerned about the Lipitor® and had a CPK check. It was over 500. He tried to determine if the muscle pain was due to the Lipitor or post-polio syndrome.

On the first visit, Lipitor® was stopped for a month and followed CPK level to see what happened. In the first month off Lipitor®, he was at 327 and admitted he had overdone it before that visit. Dr. Vandenakker kept him off the Lipitor longer and followed the CPK and it went down gradually; finally down to 175. He also reported feeling much better as the CPK levels were improving and was off the Lipitor®. He had much less muscle pain, felt stronger and could do a lot more.

Dr. Vandenakker has not seen him for almost a year but he is still followed by a cardiologist. His cholesterol remains an issue. They discussed the different options to lower cholesterol. He wanted to do it with diet only. He read an article in the paper on a diet from Canada that was very effective and Dr. Vandenakker sent a copy to him.

Cardiology is following him. Looking at the most recent notes, he is on Zetia® rather than any of the statins. His cholesterol is still somewhat elevated; acceptable but not quite where they want it. He is the only patient Dr. Vandenakker followed CPK levels. It was interesting to see what happened. More typically, Dr. Vandenakker sees patients with much milder symptoms and not knowing whether it is the statin or not.

- No changes in other meds the patient was taking
- No change in the calcium channel blocker
- Patient was doing a yoga program after his pain improved.
- After being taken off the Lipitor®, his level of activity increased. The longer off the Lipitor®, he was doing more and having almost no pain.

- Discussed study of patients with myalgias, drug therapy vs. placebo
- Study using Zocor - when the dosage went up the myalgias went up also
- Medical literature does not recommend monitoring CPK levels
- Should we routinely check CPK levels in our post-polio patients?
- Information throughout the polio community that statin drugs may be a problem and a number of patients are being put on them by their primary physicians and do not take them. When asked what they should do, Dr. Vandenakker tells them to start the meds and monitor the symptoms. They are not going to die from post-polio syndrome or muscle pain. Patients with cardiology risk factors should follow their cardiologist's instructions.
- This topic is so interesting because having muscle pain is so common in post-polio. We can't say if the symptoms get worse. We do know if it is the statin drug and if the patient continues to have muscle pain it is a different cause.
- Takes six to eight weeks to see a response in the lipid levels.

Question: If you have a post-polio patient who has muscle pain at baseline, is there rationale for six weeks on/off and then back on to see if their symptoms change? Are we having a negative effect from these meds?

Response: There is a low incidence of muscle pain with the statin and the cardiovascular risks far outweigh the other problems.

Question: There was a comment that there is no downside in getting the CPK level. Sometimes other patients come to us that we are not following on a regular basis. If I want a CPK and it is borderline abnormal, what do others do? Do you have to cut off or do you think it might be exercise-induced?

Response: If your follow up with someone is limited, the primary care doctor might not appreciate it.

- The patient example given is highly educated and aware of symptoms that are impacting his life. A lot of folks are not aware. Could we be using something that is causing a patient's functionality status to be lower than what it would be otherwise? What if these meds are having more of an effect on post-polio patients than others and what if it is leading to a reduction in function that impacts his life?
- Research on this would require a large population.
- Have seen a lot of these complaints in non-polio group. Sixty-six year old man started on Lipitor® and then had trouble with the exercise.
- Talked about doing some research connected with these calls and possibility of getting a few questions answered about the drugs discussed today.
- For a survey through our polio physicians network, we would have to have some very well thought out questions.
- Suggest not just looking at patients in clinics but also in support groups where they are not as symptomatic.

- Internet has lists of meds that post-polio patients should not take. Statins are probably on some list.
- In previous years our Medical Advisory Committee advised us not to create lists and it was a question for us as to what should we do with the lists that are out there?
- We should not change what we are doing as an organization. There may be a risk that you have more muscle pain and increased weakness but it must be balanced against cardiac or stroke.
- Tell the patient to communicate with their primary physician and raise the concern that they are aware of the possible side effects from the statins. You are giving the right advice.

Dr. DeMayo asked Joan Headley if these phone calls might be a source of comments or bullet points from a lay person's standpoint, for their newsletter. She will write some brief bullet points that will be reviewed by the speaker. The next newsletter will be out in November.