DiaCeph NPH Monitoring Instructions

For 6-Marker 5-Day Monitoring Form and Shunt Outcomes Flow Chart By Stephen Dolle, Dolle Communications Revised 11.20.18

DiaCeph Method and Monitoring Overview

The following are user instructions for the DiaCeph 6-Marker 5-Day Monitoring Form and Shunt Outcomes Flow Chart. These instructions will enable the collection of clinical data via six (6) clinical markers, and manual plotting on the DiaCeph Shunt Outcomes Flow Chart. The results will help in determining the functionality of a CNS shunt system and approximate ICP (intracranial pressure). The markers are "color coded" here and on the form, and the same so color scheme should be used in plotting the results on the Flow Chart. If obtaining a hydrocephalus monitoring consult from me, I will also interpret your results and provide a written report that you can share with your treating physicians. Your neurosurgeon may similarly want to interpret the results.

The DiaCeph Monitoring Form contains six (6) non-invasive clinical markers for hydrocephalus and NPH, whose results are then plotted on the DiaCeph +/- 3-Value Flow Chart. The results of the monitoring help approximate ICP, shunt performance, and shunt outcomes over a period of time – hours, days, weeks, or months. The chart can also serve as a historical summary of shunt outcomes for a patient. The monitoring form and instructions evaluate six (6) clinical markers common in NPH and hydrocephalus. These may also be substituted with other markers that are more predominant to a particular patient. A small percentage of patients also do not experience headache with NPH or hydrocephalus, and this makes ICP approximation a bit more difficult in these individuals. This monitoring also requires open communication and cooperation with the user patient. Below, are the six clinical markers used in this 3-session per day DiaCeph Monitoring Form.

FORM: (3) Monitoring Sessions/Day 5 Days	Head Eye Pain 3xD	Incontin 3xD	Cog/Game Score	Head Down(2) 3xD	Activity Perf 2xD	#Good Steps 3xD
Patient:	N-3 Add +/- Value	N-3	Score/N-3	N-3 Eval <u>↑/↓(</u> +/-)	N-3 w Notes	N-3 Same Course
	*Use this line for NOTES					
Day Date						
Upa.m. Sleep Quality: Good Fair Poor					*sleep note	
One-hour later/Time						
Afternoon/Time						
Day Date						
Upa.m. Sleep Quality: Good Fair Poor					*sleep note	
One-hour later/Time						
Afternoon/Time						
Day Date						
Up a.m. Sleep Quality: Good Fair Poor					*sleep note	
One-hour later/Time						
Afternoon/Time						
Day Date						
Upa.m. Sleep Quality: Good Fair Poor					*sleep note	
One-hour later/Time						
Afternoon/Time						
Day Date						
Upa.m. Sleep Quality: Good Fair Poor					*sleep note	
One-hour later/Time						
Afternoon/Time						

Monitoring Form Markers 1 - 6

- (1) Head Eye Pain 3xD N-3; add +/- Value from Head Down (over/underdrainage)
- (2) Incontinence 3x Day N-3
- (3) Cognitive/Game Score 1-3x Day Score/may be substituted
- (4) Head Down Pressure/Pain 3x Day 1st N-3; 2^{nd} Report as \uparrow or \downarrow (+/- Value)
- (5) Activity Performance 2x Day N-3 w Notes
- (6) # of Good Steps 3x Day N-3 use same course

How to Use the Monitoring Form Markers

(1) Head Eye Pain 3x Day N-3; add $+/-(\uparrow \downarrow)$ Head Down (over/underdrainage) This marker measures degree of head pressure and headache associated with NPH and hydrocephalus. It is used to evaluate physiologic ICP in the supine posture associated with resting and REM sleep; and in evaluating shunt overdrainage associated with upright posture. In these instructions, this marker is monitored three times per day (3xD): upon awaking in the a.m.; one hour later; and late afternoon or early evening (same time each day). Values are recorded by noting the discomfort level of pain and/or pressure in your head or behind the eyes. Values are entered on the form from N-3, where N = normal, 1 = slight pressure or headache, 2 = moderate pressure or headache, and 3 = marked or worst level of head pressure or headache. Write your results on the form in the 1st column under Head Eye Pain using the N-3 scoring method. After completing the Head Down Pressure Pain evaluation, add your resulting "+" or "/-" value (if able to determine) next to your N-3 score for that Head Eye Pain evaluation. This added value helps in determining over/underdrainage and is discussed further below.

<u>Marker Rationale</u>: A reading that improves 30-60 minutes after rising up from sleep or rest would indicate above-normal pressure, shunt insufficiency, mismatched pressure setting of the shunt valve, or malfunction with obstruction of the user's shunt system. A reading that worsens after rising up to upright posture would indicate overdrainage, over shunting, and/or mismatched pressure setting of the shunt valve.

(2) Incontinence 3x Day N-3:

This marker measures the degree to which NPH has impacted incontinence and the degree of decline in control. Monitoring should be done three times per day (3xD). Results are reported in terms of the degree of dysfunction in incontinence using the N-3 Value Scoring, where N = normal, 1 = slight effect in complaint, 2 = moderate effect, and 3 = marked or worst level for this complaint.

<u>Marker Rationale</u>: Incontinence is part of the "triad" of complaints in NPH. Abnormal readings would indicate the degree of untreated or uncompensated NPH following shunting, with the 2 and 3 Values indicating shunt insufficiency.

(3) Cognitive/Game Score 1-3x Day Choose your Evaluation Method & Score N-3: This marker measures the level of cognitive performance in playing an online game or app.

There are many cognitive games to choose from today which assess long term memory,

short term memory, concentration, and speed of decision-making. There are a wide array of online cognitive games at Lumosity, FitBrain, and among to mobile apps that can be downloaded. Most all of these games provide the user with a numerical score. But N-3 may also be used. Games requiring that you <u>recognize & recall faces</u> is an excellent choice.

In 3-session per day monitoring, this need only be completed once per day (1xD). However, you may do 3x day and during cognitive incidents. Result are best if performed the same time each day. Results are entered on the form by score/user's best score. The results can be mathematically converted to N-3 Value scoring for plotting on the Flow Chart.

<u>Marker Rationale</u>: Decreased cognitive function is associated with abnormal CSF clearance and non-physiologic ICP in both NPH and hydrocephalus. A very low score would indicate abnormal CSF clearance, above-normal pressure, shunt insufficiency, mismatched pressure setting of the shunt valve, or malfunction with obstruction of the user's shunt system. A slight or moderately low score would indicate a lesser degree of the above, or shunt overdrainage, lack of sleep, or cognitive change due to medication or alcohol intake.

(4) Head Down Pressure/Pain 3x Day; Score 1st N-3; 2nd 3rd as \uparrow or \downarrow (+/- Value) This marker measures the degree of head pressure/pain while bending over with your head down below the level of your waist. It is an accurate, but non-specific, measurement of ICP (intracranial pressure) and shunt drainage in NPH & hydrocephalus. This is achieved by noting your amount of head pressure or head pain when bent over with your head tilted downwards (below the waist) for a period of 5-10 seconds.

Use one of these two techniques depending on your age and balance level: a) Stand and bend over at the waste. Place both forearms over your thighs (just above your knees), and tilt your head down to the approximate level of your knees. Maintain that position for 5-10 seconds. Slowly stand back up. Note the change in head pressure, head pain, or headache; b) Stand in front of a chair or stationary piece of furniture, and bend over and place one of both hands on the chair for stability, while tilting your head downward to a level just above the knees. Maintain that position for 5-10 seconds. Slowly stand back up. Note the change in head pressure, head pain, or headache.

This should be monitored three times per day (3xD): upon awaking in the a.m.; one hour later; and late afternoon or early evening (same time each day).

Note: A small percentage of individuals with NPH and hydrocephalus will experience little to no head pressure and headache during non-physiologic ICP. In these individuals, they may only be able to observe and report a sensation of abnormal pressure in this head.

Some patients will experience <u>two separate sensations</u> that can be used as assessment values from this postural maneuver. The 1^{st} is your initial sensation of <u>pressure/pain</u> (first 3 seconds) when you first place your head downwards. This maneuver measures shunt flow from your last posture. The 2^{nd} assessment then measures any "change" in <u>head pressure/pain</u> you feel 3-10 seconds after your head is titled downwards. The second

evaluation is more a measurement of ICP (intracranial pressure) and overall drainage rate (over/underdrainage) thru your shunt.

Write your <u>head pressure/pain</u> results in the Head Down column using the N-3 Scoring Scale: where N = normal, 1 = slight worsening, 2 = moderate worsening, and 3 = marked worsening. However, you may also notice an improvement if your shunt is <u>overdraining</u>. So, the 2^{nd} Evaluation here is to add a " $\underline{\uparrow}$ " or " $\underline{\downarrow}$ " or "NC" next to your score, indicating how your <u>head pressure/pain</u> changed in the downward position. Write $\underline{\uparrow}$ for "increasing" pressure/pain, a $\underline{\downarrow}$ for "lessening improving" <u>head pressure/pain</u>, and NC for "no change."

If you like, you may also include an initial <u>pressure/pain</u> sensation during the first few seconds of \downarrow (improving). This would indicate slight overdraining. But if it quickly changes to increasing head pressure, then you write \uparrow for increasing. It is the feeling you get after those initial seconds, that is the score you report. You can have slight shunt underdrainage and slightly elevate ICP (as I am now), and feel a momentary relief in headache followed by increasing head pressure. When your Head Down score is 2 or 3 (N-3), the pain or pressure will be obvious from when you first put your head down, and remain constant or increase. If it's <u>normal</u>, it should not change the longer your head is downwards. If you sense an initial change in <u>head pressure/pain</u> followed by it changing after 5-10 secs, report BOTH by writing two " \uparrow " or " \downarrow " or "loc" side by side on the form next to your N-3 score. \uparrow indicates "increasing" pressure/pain, \downarrow indicates "lessening improving" pressure/pain, and NC indicates "no change." A typical result (I took mine a few minutes ago), will look like this: **Head Eye Pain = +1; Head Down Pressure/Pain = 1**

This above represents a **Head Eye Pain** level of 1 sitting at my desk. **Head Down Headache Pain** levels in the first few secs after putting my head down, were slightly improved. So I wrote a \downarrow for slight momentary improvement. But then a few secs later, I felt increasing head pressure that became stronger and constant, where I wrote a \uparrow . Overall, my predominant response was increasing or \uparrow , and with a head pressure level of 1 (N-3). Therefore, my **Head Down** test earns a total score of $1 \downarrow \uparrow$.

Converting $\uparrow \downarrow$ and NC to "+/- Values" and ICP (intracranial pressure)

The \uparrow and \downarrow arrows in this monitoring also correspond to "+ **and** – **Values**" in the DiaCeph Test format for estimated ICP (intracranial pressure); where \uparrow = +, and \downarrow = -, and \uparrow or + for elevated **ICP**, and \downarrow or – for low **ICP**. These ICP values then speak to <u>underdrainage</u> or <u>overdrainage</u> thru the user's <u>CNS shunt system</u>.

In my monitoring today of these two markers, the " \uparrow " mark is converted to a "+" Value and added to my **Head Eye Pain** score, making it "+1" or a slightly increased level compared to physiologic ICP for me. My initial momentary relief in headache, or \downarrow arrow, was only temporary and indicated that my shunt was slightly overdraining while in the sitting posture. But, my predominant finding was \uparrow after a few seconds. So I get a "+" **Head Down** value, making my overall score $1\downarrow\uparrow$ in the **Head Down** test. The results indicate my shunt is slightly overdraining while sitting, but overall its CSF output is <u>underdraining</u>, and that I have a <u>slightly raised ICP</u> for me. This finding is also supported in my cognitive and other values.

<u>Marker Rationale</u>: Blood pressure and ICP normally increase with your head in the downward position. A sensation of increasing and above-normal pressure would indicate increased ICP, shunt insufficiency, mismatched pressure setting of the shunt valve, or malfunction with obstruction of the user's shunt system. A sensation of lessening pressure would indicate overdrainage, over shunting, and/or mismatched pressure setting of the shunt valve. If you are able to observe a 1st and 2nd pressure response, the 1st would indicate the current flow of your shunt as to underdraining or overdraining, and the 2nd would indicate whether your ICP is above-normal or below-normal for you. It is the 2nd reading that we are concerned with and will be plotted on the Flow Chart.

(5) Activity Performance 2x Day Score N-3 w Notes:

This marker measures your combined cognitive function, physical health, and restful state in terms of your productivity using the N-3 Scoring Scale, where N = your normal or best functional state, 1 =slight decrease, 2 =moderate decrease, and 3 =marked decrease. This should be done twice per day (2xD). You may write in a sleep note in the space for upon awaking. You may also add a 1 or 2 word note regarding an activity or other health issue that may be compromising your performance. This can be written next to your score. You might also get input from others around you if you are unsure on your performance status.

<u>Marker Rationale</u>: Decreased activity performance is often associated with cognitive decline from abnormal CSF clearance and non-physiologic ICP, both in NPH and hydrocephalus. A markedly low performance score would typically indicate abnormal CSF clearance, abovenormal pressure, shunt insufficiency, mismatched pressure setting of the shunt valve, or malfunction with obstruction of the user's shunt system. A slight or moderate drop in performance could indicate the above, but also shunt overdrainage, poor sleep, stress, or cognitive changes from medication or alcohol intake.

(6) # of Good Steps 3x Day N-3 Use Same Course:

This marker measures the number of good steps taken by the user before a mis-step. This can be done in a hallway, walkway, stairway, or similar course. It is important that the same course be used during each session, with the exception of the 1^{st} evaluation of the day, which may be done in the walkway or path between the bedroom and bathroom. This should be done three times per day (3xD) and on the same courses. Please be mindful to wear the same footwear during these assessments, i.e. slippers upon awaking, same or similar shoes in the 2^{nd} and 3^{rd} monitoring so your results will be comparable. Add notes of other complicating health issues in the low back, legs, or feet, that may have contributed to a low score. Write this next to the score, or in the open row above it for that day.

Results can be reported as either the number of steps taken without a mis-step, by write in the number on the form, or by using the N-3 Scoring Scale, where N = your normal or best walking, 1 = slight decrease, 2 = moderate decrease, and 3 = marked decrease.

<u>Marker Rationale</u>: Decreased gait, balance, and walking skill is often associated with NPH and hydrocephalus, from abnormal CSF clearance and non-physiologic ICP. A markedly poor score could indicate abnormal CSF clearance, above-normal pressure, shunt insufficiency,

mismatched pressure setting of the shunt valve, or malfunction with obstruction of the shunt system. A slight or moderate drop in performance could indicate the above, but also shunt overdrainage, poor sleep, stress, or cognitive changes from medication or alcohol intake.

Additional Instructions:

The online **Cognitive/Game Score test** need only be done once per day, preferably at the same time each day. Should you be experiencing problematic cognitive incidents, you may add additional evaluations to the monitoring form. The **Activity Performance** marker can be omitted during your 1st monitoring each day. If you are concerned about your cognitive status upon awaking, you may add a cognitive evaluation upon awaking. On the **# of Good Steps** monitoring, first determine which <u>walkway & steps</u> you will use, and use the same course for all your monitoring. For instance, do your first **# Good Steps** monitoring each day during walking from your bedroom down the hallway, etc. after getting out of bed. Then, you may use a different path or walkway during the day as long as you use these same courses for each day's monitoring session. Note on the monitoring form if you have any difficulty with low back pain, leg, or foot complaints during these evaluations. There is space for <u>medical notes</u> on the monitoring form in the horizontal rows adjacent to Day and Date.

These <u>instructions</u> and accompanying <u>monitoring forms</u> provide for three (3) monitoring sessions per day. Additional monitoring sessions may be done each day by utilizing the next day's entry space – provided you note the Day & Date on the form.

Monitoring is typically done for ten to fourteen days, with 3-6 monitoring sessions per day. In many cases, (3) monitoring sessions per day is all that is needed. For initial monitoring, I recommend three (3) times per day - for ten days. It can be stopped after 5-7 days if the results are the same each day. The accompanying 5-day monitoring form has spaces for three monitoring sessions per day, spanning five days. For ten (10) days of monitoring, you will then use two forms.

Later on, and especially following shunt adjustment, it might be necessary to monitor more times per day, beginning upon awaking in the am, 9am, 12 noon, 3pm, 6pm, and 9pm or bedtime. I can give specific instructions on how long, and how often, you need to do this.

Often it is necessary to add "interventional testing" to further evaluate results which are unclear. This may include monitoring utilizing Trendelberg postures, examination of your shunt system and valve reservoir, special cognitive challenges, reporting of nausea, changes in balance, changes in vision, and visual, auditory, and tinnitus sensory complaints.

Let's run through your 1st monitoring session of the day:

Your first monitoring session should begin immediately upon awaking in the morning. You should have a blank form on a clipboard or binder next to your bed.

Begin by writing in your **name**, **day**, and **date**. Below that, write in the **time** you awoke in the space next to "Up____a.m." Next, **circle the quality of sleep** from one of these three (3) selections. "Sleep Quality: Good Fair Poor."

<u>I recommend completing these markers in the following order:</u>

Head Eye Pain 3xD N-3; later add +/- Value from Head Down marker

Note the discomfort level of pain in your head and behind the eyes, and write it as a Value between N and 3 in the 1^{st} column on the Monitoring Form. Use the range for N = normal, 1 = slight, 2 = moderate, and 3 = marked or worst level for this complaint marker. Write this value on the form on the appropriate line and Head Eye Pain column. When finished, proceed to the Incontinence marker.

Incontinence 3xD N-3

Note the degree of dysfunction in your incontinence at that moment, and using the N-3 Value Score, where N = normal, 1 = slight incontinence, 2 = moderate level of incontinence, and 3 = marked or worst level of incontinence. Write this value on the form on the appropriate line and Incontinence column. When finished, proceed to the Head Down marker.

Head Down Pressure/Pain 3xD 1st N-3; 2^{nd} 3rd Score as \uparrow or \downarrow (+/- Value) Within 10 minutes of getting up from bed in the morning, do this Head Down assessment.

This marker measures the degree of head pressure and physiologic ICP associated with NPH and hydrocephalus. This monitoring is done by noting the change in head pressure, head pain, or headache when your head is tilted downwards for 5-10 seconds, and whether that pressure or pain is increasing (\uparrow) , or lessening (\downarrow) with your head downwards for 5-10 secs.

Use one of my two techniques described in the "How To Use" section above to do this twostage evaluation while bending over for 5-10 seconds.

There may be two observations you get from this postural maneuver. Some patients will only observe one. SEE the detailed discussion on this in p. 3 & 4. The 1st is your initial sensation to tilting your head downwards. The 2nd is your predominant and lasting sensation after 5-10 seconds, and more indicative of overall ICP. If you feel two distinct pressure responses, write each down using the $\uparrow \downarrow$ arrows next to your **Head Down** value (N-3) on the form. Use the Scoring Scale N-3: where N = normal or no change, 1 = slight change, 2 = moderate change, and 3 = marked change. Next, convert your $\uparrow \downarrow$ arrows and place a "+" or "-" next to your N-3 Value & next to your **Head Eye Pain** value ("+" indicates increasing pressure feeling, "-" indicates lessening pressure). Proceed to the # of Good Steps marker.

of Good Steps 3xD N-3 Same Course

Next, evaluate your walking when first getting out of bed in the morning. Your first # Good Steps session of the day should be from your bedroom to the bathroom or hallway, etc. where you take your 1st steps of the day.

Be mindful to wear the same footwear during these assessments, i.e. slippers upon awaking, and same or similar shoes in your 2nd and 3rd monitoring of the day so results are comparable. Add any notes of problems with your low back, legs, or feet. Write this score in the row under # of Good Steps for that day and session. Write in between N-3 on the Scoring Scale, where N = your normal or best walking, 1 = slight decrease, 2 = moderate decrease, and 3 = marked decrease.

This completes your first monitoring session of the day. You will do Cognitive/Game Score & Activity Performance monitoring in your 2nd and 3rd sessions/day as discussed below.

For your 2nd session of the day, approximately one hour later, write in the TIME on the form. Next, perform and write in the results of your Head Eye Pain, Incontinence, Head Down, and # Good Steps markers as you did earlier. Now proceed and do your online Game Score. This need only be done once per day (1xD). So you have the option to do this either during your 2nd or 3rd monitoring session. It's best if performed about the same time each day.

Cognitive/Game Score may be substituted with other test using N-3 scoringFor this evaluation, play your online Game as described under Hot To Use, and enter your numerical score/best score in the appropriate Game Score column. Next, proceed to the Activity Performance marker.

Activity Performance 2xD N-3 w Notes

In this assessment, all you need do is write in a value on the form which reflects your productivity at the point of the day. Use a score between N-3, where N = your best or most productive normal, and 1, 2, 3, as progressively worse values as described above. This should only take a moment to complete. Ask for input from others around you if unsure.

Later in the day, between 3pm and 7 pm, perform your 3rd session of the day. Write in a word next to the TIME of the activity you were doing prior to the monitoring, eg. laying down, in yard, office, garage.

You have now completed one day's worth of **DiaCeph monitoring**.

In some cases, you may be asked to perform "Interventional Testing," where you monitor after specific activities or to evaluate a new marker. For this, you may use the current form, the two-day form from my web site, or wait for my instruction with a new form.

For my patient consults, I insert patient data into the Flow Chart, and will write a report of the information. Patients and physicians are welcome to do this themselves.

Below, I explain how patient data from monitoring is plotted on the Flow Chart. In the past, I've used the Microsoft Excel program. I wanted to make this new Flow Chart available so patients and physicians can plot results themselves. If there were a DiaCeph app available, this would be done automatically within the app.

Plotting results on the DiaCeph Monitoring Shunt Outcomes Flow Chart

You will need seven colored magic markers, or colored pencils, in the following colors:

Black: (1) Head Eye Pain 3x Day N-3; add +/- Value Head Down test

Yellow: (2) Incontinence 3xD N-3

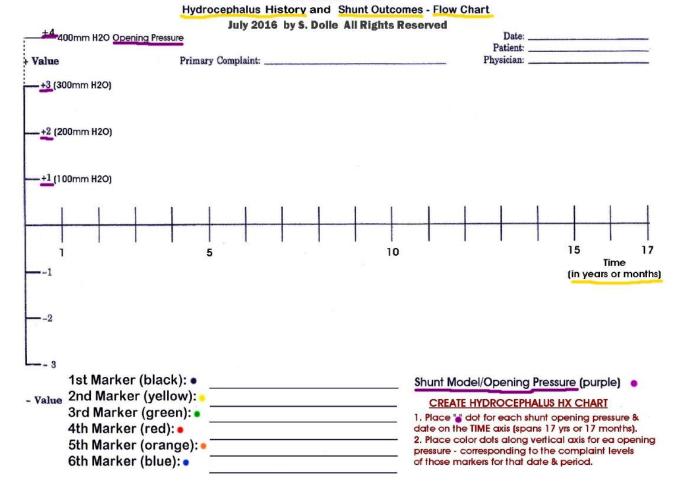
Green: (3) Cognitive/Game Score 1-3x per day may be substituted

Red: (4) Head Down Pressure/Pain 3x Day 1st N-3; 2^{nd} 3rd Score $\uparrow \downarrow (+/-)$

Orange: (5) Activity Performance 2x Day N-3 w Notes
Blue: (6) # of Good Steps 3x Day N-3 Use same Course

Purple: Shunt Model/Opening Pressure

DIACEPH TEST



This Flow Chart has 17 equidistant hash-lines on the **x-axis** representing **time** in hours, days, weeks, or months – depending on what you are plotting. With this first round of monitoring spanning 3 sessions per day, we will plot 5 days of data on each chart.

The **y-axis** has "+" and "-" Values between N-3. Marker (1), (2), (3), (5), and (6) data are plotted on the "+" portion of the **y-axis**. Marker (4) data is plotted on the side of the **y-axis** depending on "+" or "-" of the **(4) Head Down** test.

Lay out your completed Monitoring Forms next to a blank Flow Chart. Fill in the form with the name, date, physician, and primary complaint. With a black pen, draw a longer vertical hashline over every 3rd line on the **x-axis** as these will represent **days** in this series. On the "-" side of the **x-axis**, write in the actual dates (5 day/dates in total on each form). Now plot the data from the (1) **Head Eye Pain** marker with the black marker beginning on the first **x-axis** hash-line, and plotting the remaining data from this column on the form over five days on the Flow Chart. The last data point should be on the 15th x-axis hash-line. Now, do the same for the (2) Incontinence, (3) Cognitive/Game Score, (5) Activity Performance, (6) # of Good Steps - remembering to plot these with their respective marker color.

Once these above markers have been plotted, use the red marker now to plot the (4) Head **Down** data, where "+" and "-" values determine if the data goes on the + or - side of the xaxis. Plot the remaining data from the column. Now, using the same color markers, take a small ruler and draw lines connecting the data points for each marker – remembering to use the correct color marker for the line.

Next, plot the next 5 days of marker data from the 2nd Monitoring Form, repeating the above.

This concludes the DiaCeph Monitoring Instructions and posting of monitoring data on the Flow Chart.

For those wishing to plot other/historical shunt outcomes data, plot the patient marker portion first as described above, and then use a purple marker to plot data points for the shunt opening pressures pertaining to the respective monitoring dates. On the x-axis, write below each hash-line "weeks" or "months" to reflect the reporting period you are charting.

If you have any questions, please contact me per my contact information below.

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